

## Welcome



elcome to the latest issue of Dementia together – Alzheimer's Society's magazine for people with dementia and their carers, families and friends.

Planning and creating the last issue with the Young Dementia Thematic

Group was an incredibly rewarding experience. I hope you can already see the impact of what we learned working with them. Expect to see more from this in future!

We cover a wide range of experiences in every issue, and your August/September magazine is no exception.

The creativity and amazing capacity of people to adapt to life with a diagnosis shines through in articles about Maria (pages 8–11), Steve (page 14) and many others.

The incredible challenges faced by carers are also here, such as in our interview with Dalwinder (pages 30–33) and a letter from Gareth (page 36).

Our ideas and advice include how to deal with feeling unheard (page 16), products to help with snacks and mealtimes (pages 28–29), deciding when to step in to help someone (page 35) and more.

We're analysing your responses to the readership survey included in the last issue. Of course, we always welcome your feedback and ideas so we can improve what we do – please use the magazine contacts to get in touch.

Danny Ratnaike, Magazine Editor



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

Dementia together is the Alzheimer's Society magazine for anyone affected by dementia. Contact us on

magazine@alzheimers.org.uk, 020 7264 2667 or 020 3929 5117.

or write to us at Magazine Editor, Alzheimer's Society, Suite 2, 1st Floor East Wing, Plumer House, Tailyour Road, Plymouth PL6 5FS. Sign up to get each new magazine by email or – if you're in the UK, Isle of Man, Channel Islands or Republic of Ireland – in print or on CD through the post. Please email magazine@alzheimers.org.uk or call 0330 333 0804 to subscribe or update your details.

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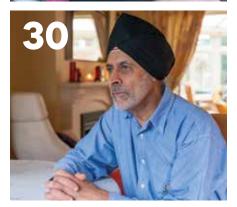
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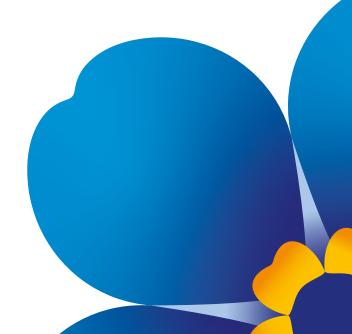
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## **Directions**

ate Lee left an immense legacy as the Society's CEO, and we look forward to announcing a new leader later this year. In the meantime, it's a privilege for me to act as interim CEO, especially at such an exciting time.

The impact of our campaigns – and all of you who take part in them – has never been clearer to see.

The inclusion of dementia in the NHS 10 Year Health Plan for England is a real win. It's something we've been pushing for ever since last year's announcement of a plan.

Many consultations, meetings, interviews and campaigns later, dementia will be one of only three named conditions with a specific service framework. That cements dementia as a key priority for the government.

Of course, the detail of how this is implemented is crucial. So, alongside pressing for a new Dementia Action Plan in Wales and engaging with the Northern Ireland Executive, our work is far from done!

Thankfully, we don't need to look far for motivation.

There's our knowledge that getting the right support at the right time makes a real difference. And the vision of a transformed future that our researchers keep showing us.

And there's you, the people we support and who support what we do. Thank you – I hope to see you at a Memory Walk this autumn!

Corinne Mills, Interim CEO

## News

## Dementia debate in Parliament

Alzheimer's Society contributed to a high-profile House of Commons debate this summer, helping to put dementia firmly on the political agenda.

During the debate, tabled by South Devon MP Caroline Voaden, over 50 MPs spoke passionately about the scale of the UK's dementia crisis.

As well as mentioning our work, MPs also used our evidence, statistics and insights to inform their speeches.

This debate is a step in the right direction to making dementia a priority for the government.

The urgent need to improve dementia care was a key theme. In response, Minister for Social Care Stephen Kinnock MP said, 'All those who have dementia deserve to receive high-quality care. We must have a workforce that is equipped with the skills that are needed.'

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

## **Appeal success**

Our 2025 Forget Me Not appeal has been our biggest and best yet, raising over £1.5 million to fight dementia.

Dame Judi Dench, Sir Jonathan Pryce, Anna Richardson, Meera Syal CBE, Gareth Locke-Locke and countless other celebrities helped raise the appeal's profile by wearing Forget Me Not badges.

We also had incredible support from our corporate partners, including British Airways, One Stop, CBRE and Topps Tiles.

Heartfelt thanks to our 1,800 incredible volunteers who collected in over 400 Morrisons stores, and to all of you who hosted or attended Forget Me Not tea parties. We couldn't have done it without you!





## **Society at Pride**

Every year, we attend over 30 Pride events to show our commitment to supporting LGBTQ+ people affected by dementia.

So far in 2025, we've been at Pride events including Portsmouth, Oxford and Liskeard – our first ever in Cornwall.

Look out for us throughout the rest of August and September, including at Leicester, Milton Keynes and Herts Pride in Watford.

















Find out more about living with dementia as an LGBTQ+ person at alzheimers.org.uk/lgbtq

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

### **10 Year Health Plan**

We are pleased that people living with dementia have been listened to in the newly published 10 Year Health Plan for England.

The plan outlines a shift in the way the NHS will work in future, providing more preventative services and health care closer to people's homes.

We look forward to seeing the 'blueprint' for high-quality dementia care, which the government plans to publish in 2026.

### Wales Takes on Dementia

If you live in Wales, add your name to our new Wales Takes on Dementia petition.

We want to show how much support there is for a new Dementia Action Plan that works for people in Wales.

We estimate there are 51,000 people living with dementia across Wales – and the condition touches the lives of thousands more.

Help us make dementia a priority by showing the strength of our nation and the power of standing together. Sign the petition at alzheimers.org.uk/wales-petition

# NI ministerial meeting

In July, Alzheimer's Society had a positive meeting with Mike Farrar, Interim Permanent Secretary in Northern Ireland's Department of Health.

Fiona Carragher, our Chief Policy and Research Officer, and team discussed the urgent dementia challenge with him and shared recommendations. They talked about improving diagnosis, supporting carers and addressing health inequalities. The meeting reinforced our shared commitment to change and the importance of collaboration.

### **Final NHS drugs** decision

We are disappointed that lecanemab and donanemab - the first approved drugs in the UK to slow down the progression of Alzheimer's disease will not be available on the NHS.

However, we are positive about progress towards identifying new therapies.

New treatments for Alzheimer's are on the horizon - in fact, there are more in development than ever before.

There's lots to learn from lecanemab and donanemab too.

We hope that the data from their use privately in the UK and overseas will be shared and analysed to help inform future treatments.

We also fund research into all types of dementia so that no one is left behind.

Read about our research and latest news at alzheimers.org.uk/ research

### **Ask about** dementia, Ask about Alzheimer's

It's World Alzheimer's Month this September, and Alzheimer's Disease International (ADI) will be encouraging more people to ask questions and learn about dementia. Now in its 14th year, the international campaign raises awareness and challenges stigma. The theme for 2025 is 'Ask about dementia. Ask about Alzheimer's'.

Using the hashtags #AskAboutDementia and #AskAboutAlzheimers, ADI wants to normalise more conversations and learning about the condition and its impact.

On World Alzheimer's Day, 21 September, ADI will also release its annual World Alzheimer Report.

To find out more and get involved, visit alzint.org/ world-alzheimers-month

### **Insurance United FA partnership Against Dementia**

Our Insurance United Against Dementia (IUAD) campaign has hit its initial £10 million fundraising target.

Since 2017, over 140 different insurance businesses and organisations have come together to fundraise and mark our annual flagship event, Insurance Day for Dementia.

The campaign has made a massive difference to our work. A £2.4 million grant secured by IUAD helped get our Companion Calls service off the ground and enabled us to hire more advisers to support people affected by dementia.

It's also led to over 18,000 insurance professionals becoming Dementia Friends, who are doing a sterling job to raise awareness. Find out more about Insurance United Against Dementia at alzheimers.org.uk/IUAD

### Society volunteers honoured

We're delighted that three tireless Society volunteers were awarded British Empire Medals in the King's Birthday Honours list.

Since her diagnosis at 60, our Trustee Chris Maddocks has become a powerful advocate of people living with dementia.

Dr Jou Watson, who was diagnosed with Alzheimer's disease in her mid-50s, is a Society Ambassador and part of the 3 Nations Dementia Working Group.

Dementia Friends Ambassador Emily Wilson has also been recognised. She was inspired to support people in Northern Ireland after her late husband Jim was diagnosed with young-onset dementia.

## extended

Our powerful partnership with the Football Association (FA) has been extended for the 2025-26 season.

So far, the partnership has raised over £1 million and created awareness about dementia and where to access support.

In that time, we've made Wembley Stadium more dementia friendly for fans and opened a memory café there. We've also worked with clubs across the country to educate fans on the importance of diagnosis.

This will be the fifth year of the partnership. In the upcoming season, the England men's senior fixture against Wales in October will be an Alzheimer's Society International. For more about the FA partnership, see alzheimers.org.uk/fa



### Listen to our podcast

Did you know that we produce a podcast to accompany each issue of Dementia together?

So, as well as reading an article, you can also hear more from the people who feature in it.

You can listen to and subscribe to the Dementia together podcast on a selection of podcast platforms, including Apple and Spotifu.

Look out for the newest episode in early August at alzheimers.org.uk/podcast







### **Memory Walk**

This autumn, honour someone special by taking part in Memory Walk 2025.

Join the thousands of people across the UK who've already signed up to raise vital funds for life-changing support and groundbreaking research.

It's a chance to share memories as well as raise awareness. Every step takes us closer to a future free from dementia.

Be part of something powerful. Walk with us.

Sign up to a Memory Walk near you at alzheimers.org.uk/memorywalk

## Are you entitled to benefits?

If you're affected by dementia, you may be eligible for a range of benefits to support your care needs or caring responsibilities.

Even though not all the government's proposed welfare reforms have been confirmed, it's a good idea to find out what you may be entitled to under current rules.

A good place to start is our updated benefits factsheet, which includes advice on Universal credit, Personal independence payment (PIP), Carer's allowance and much more.

For our Benefits for people affected by dementia (413) factsheet, visit alzheimers.org.uk/publications or call 0300 303 5933.

## Honest product reviews

Sometimes it's hard to know whether an assistive product will make a difference to your life when you only have a short description to go on.

That's why our shop now features product blogs by reviewer Michael Booth, who has young-onset dementia (and who also features on page 17).

From music players to kitchen gadgets, Michael has taken several products through their paces and scored them too.

Find Michael's blogs at shop.alzheimers.org.uk





## Check your boiler now

It's Gas Safety Week from 8–14 September, and now's the perfect time to make sure your gas boiler is working before the cold weather arrives.

Too many of us leave it until winter, when we already need the heating to work and when gas engineers are in high demand.

Our Gas Distribution Network partnership (see pages 24–25) means we can provide advice on free boiler checks, energy efficiency, gas safety, the Priority Service Register and more.

Call our Dementia Support Line on **0333 150 3456**.

## Don't miss...

Dealing with how it feels when you have dementia and people aren't listening to you. **See page 16**.

Del and Margaret saw an idea through from talk to action, helping bus drivers to be more supportive. **See page 18**.

An energy partnership is helping people affected by dementia boost safety and cut bills. **See page 24**.

People tell us what they think of products designed to help with eating and drinking. See page 28.

Which local authority do you contact if someone's moving to a care home in a different part of England? **See page 34**.

# 'Have a good life'

For Maria in Essex, accepting her dementia diagnosis and focusing on what she enjoys has been vital. Margaret Rooke learns how she uses her creativity and her voice.





## I have never sat in a corner thinking, "Oh God, when am I going to die?" or "What is going to happen to me?

hen she was asked by her local council to design a logo for dementia support, Maria created a beautiful trio of forget-me-nots.

She included new shoots on the image to represent the help and new paths that can spring up for people with dementia.

Those new shoots could also symbolise Maria's own impact. Now 69, she has found ways for her own special brand of positivity to reach far and wide.

#### **New paths**

Maria and her husband Norman volunteer with Time for Dementia. Through this, they help educate healthcare students about what life is truly like for people affected by dementia.

Maria has also discovered a whole new hobby – one that was far from her thoughts before she was diagnosed with vascular dementia 15 years ago.

In her living room, surrounded by paper and acrylics, she paints beautiful pictures. She donates many to hospital wards to showcase the talents that people with dementia can develop.

Maria has been involved in her Dementia Voice local group too. They explain to businesses and organisations what they need to do to become more accessible for people with dementia.

'The changes they made have been life changing and help us live as normally as possible. They mean I can use the airport and visit my family.

'Being in this group made me feel important,' she says. 'It showed my voice is important.'

### Struggles and acceptance

Thinking back to when Norman insisted she discuss her memory problems with her GP, Maria says

she'd had no idea she had become forgetful.

'I thought, "Oh, there's nothing wrong," but I went to make him happy and shut him up basically.'

However, she had been leaving the cooker on, leaving taps and lights on and forgetting words.

'Words have always been my main struggle,' says Maria. 'The more I think about them, the more stressed I get.

'I try to explain what the word is that I'm searching for and people don't understand, and I struggle more.'

The GP didn't think anything was wrong, but the couple talked to a psychologist who referred her for a memory test. After having an MRI scan, she was told she had vascular dementia.

Unusually, Maria says this didn't have a big effect on her.

'I have never sat in a corner thinking, "Oh God, when am I going to die?" or "What is going to happen to me?"

'I just accepted it. The worst thing you can do is dwell in your miseries. That's how life is wasted.'

Two years ago, she was also diagnosed with Alzheimer's disease.

'I've always been a strong person,' says Maria. 'I've had a few traumas in life but I've got on with it.

'I have my kids, I have my grandkids. I'm never going to give up because I have them to look forward to.'

### **Patience and time**

Maria was born in Gibraltar, which is where she met Norman. It's also where her daughter, son and grandchildren live.

They only see their mum if she flies over or if they come to Essex, and it took a while for them to take in the diagnosis.

'I find travelling very stressful now, but I want to see them as much as I can because I love them all to bits,' she says. Maria says Norman is a wonderful support.

'Patience is very important if you are caring for someone with dementia. If we're arguing, instead of carrying on, Norman will walk away and that will calm things down.

'But I say to Norman, don't assume that you know something about me. Ask me and listen to what I have to say.'

She also stresses that carers need time for themselves. Norman goes to matches at his local football club, as well as enjoying cups of tea with his friends and time in his garden.

Maria says taking this time is 'like medicine' to carers, meaning they can better support the person with dementia too.

### 'My own cocoon'

Maria and Norman used to go to local groups for people affected by dementia. But Maria now prefers the quiet and focus of time at home.

'I prefer to be in my own cocoon,' says Maria. 'I'm not a loner, I just like to be at home and paint. I don't feel the need to be out there with all the noise in groups.'

Painting has been life-changing for Maria. She tried arts and crafts classes after she was diagnosed, and soon was painting Christmas and birthday cards, and then full-scale pictures.

'When I'm in my little corner, painting, I'm in a little world of my own,' she explains.

'I love pictures, sometimes putting my own spin on what I've seen other people paint, like waterfalls or vintage ladies. I always put something of me in there. If I'm painting scenery outside, I just paint what I see.

'I show my emotions in my abstract work. I start painting and if I'm not feeling it, I stop. I have to be in the right frame of mind.'

### Seen by thousands

Maria's forget-me-nots image for Inclusive Dementia Communities in north Essex has been seen by thousands.

The logo is used to promote organisations with a good understanding of dementia – on stickers, badges, tablecloths, pop-up banners, certificates and more.

Through Time for Dementia, Maria and Norman have regular Zoom meetings with nursing and other healthcare students.

'We talk about how to deal with us, but stress that everyone's different.

'They ask lots of questions, some are personal, some are not, but I don't mind answering them. I know I'm helping people out there. We're in our second year now and we've already said we'll do next year.

'It has a big impact on me because I can see their faces and how happy they are with the meeting.

'One thing I tell them is, "Don't talk to me and look at my husband. Talk to me face to face."

'If there's something I don't understand or can't remember, I always say, "Norman?" and he answers for me, but I don't want to be ignored. I've heard many others say that too – we still have a voice.'

One of the students who saw Maria's paintings asked to display some in dementia wards to show what a person with dementia could still do

### Losing people

Maria doesn't shy away from talking about some of the difficulties dementia has brought. As an outgoing person, she used to have a lot of friends.

'Since I was diagnosed, little by little they dropped away,' she says.

'Then I made a lot of new friends by going to the dementia groups. I called that my little family. But this hurts me to say – they are dying. I'm losing them because of an illness.

'That's maybe part of why I don't go to groups anymore. I don't want to get attached to people. 'All these years I've been diagnosed, and these people I've known for a few years have died before me. How can that be? I can't understand it and I feel guilty.'

### Focus on joy

Maria focuses on things she enjoys – getting on with life, going out with Norman and traveling while she can.

'I am no longer a party animal. I've grown older now. Being at home is what I want to do.

'I have leg problems and back problems, and use a stroller or a walking stick or a wheelchair, but I can still have a laugh and a joke. I am at home, acting my age!'

Despite her painful experiences, the couple advise everybody who's recently been diagnosed to attend every group they can and meet as many people as they can. This can help in many ways.

'Have a life. Have a good life,' says Maria. 'Realise that life is going to change, but you can make it change for the better.'





I have my kids, I have my grandkids. I'm never going to give up because I have them to look forward to.

For more about
Time for Dementia,
see alzheimers.org.uk/
timefordementia or call
07562 430204.

Visit alzheimers.org.uk/involvement to find ways to influence our and others' work, including Dementia Voice local groups.



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

# **Share and inspire**

Views, updates and ideas - for and by you.

## Never done before: Kop to curtain up



ick Haith, in Leeds, has channelled his lifelong love of Leeds United and his experience of dementia into the development of a new play:

'I first started watching Leeds United when I was 14. This was back in the days that the Kop at Elland Road, United's ground, was all open to the elements, so sometimes you got absolutely drenched.

'Sport's always been a constant in my life since childhood – cricket as well as football.

'But theatre is a completely new experience for me. I never thought my passion for Leeds United would take me in the direction it has.'

#### Staying active

Being diagnosed with dementia in 2015 was a difficult time. A dark time.

'But getting involved with lots of different activities with my wife Lyn has made a massive difference. 'We're members of a DEEP (Dementia Engagement and Empowerment Project) group at Leeds Playhouse and Dementia Friendly Leeds, which is all about trying to make society more dementia friendly. We want our experiences to help others.'

### **New opportunities**

'It's through DEEP that we were asked if we wanted to contribute to a new play called Through It All Together by a local playwright called Chris O'Connor.

'It's about a couple who are big fans of Leeds United and are dealing with dementia, while the club is being promoted under its manager Marcelo Bielsa.

'Bielsa is still a big hero in Leeds even though he's not the manager anymore. There's a mural of him outside a fish and chip shop near us.

'I didn't hesitate to say yes to

getting involved. I just love talking to people about Leeds United.'

### **Collaborative process**

'Supporting the play has been a gradual process, over two years or so.

'Early on Chris came to the Corner Flag Café. This is a dementia support group at Elland Road that Lyn and I go to.

'It's an important place for us, very supportive. Through it, we've also had the chance to meet a few of the players, go into the dressing rooms and on the pitch.

'Chris sat and spoke with us about life, what joining the group means and being a fan of the club.

'We talked about our experiences of following the team, including through the Covid pandemic when we were all watching matches at home.

'We've also been to a readthrough of the script, which was a chance to comment on the things we liked and didn't like. As we sat there and listened, we could connect to it straight away.

'We also gave our feedback about the play's poster.'

#### **Uplifting experience**

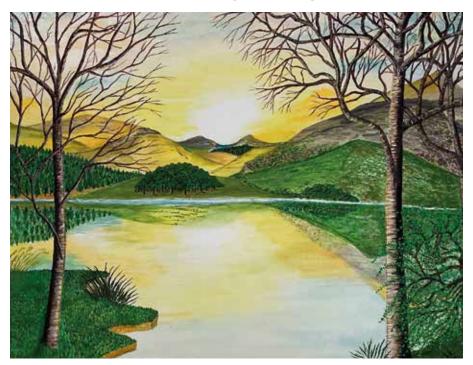
'When you have dementia, you think maybe you're not going to get listened to and get opportunities. So being involved with the play has been brilliant.

'You've got to make the effort. Things don't come to you. You have to keep on fighting.

'Getting out is good for us both.

'We haven't gone backwards. I feel like we've gone forwards and done more.'

### Letter: Serendipity, the golden hour



I decided to have a break from Alzheimer's. I wanted to fill my head and heart with love and optimism. This was the inspiration for my painting. In my mind, I tried to imagine how we would all feel on the day medical science says, 'We have found a cure for Alzheimer's.'

I wanted to paint a feeling of pure joy. I cannot tell you how my heart will sing with happiness, and the idea I would have new horizons, I will be able to explore and remember. So, to build my painting, I knew I had to make it all about the glorious sun rising.

I always try to walk on the sunny side of life. The day of the cure will be like the best sun rising on the rest of our lives. I thought 'serendipity' was the perfect word, like when they discovered penicillin. It will be a major breakthrough for the human race.

I wanted my painting to glow, it's all about the golden hour, when the sun

rises or sets. The rest of the painting is quite irrelevant, but I wanted the trees to frame and caress the sunlight. Like in family life, our loved ones hold us tight.

The branches of the trees represent our hand catchers reaching out, keeping us safe, they don't let us fall. I didn't paint leaves on the trees as I wanted you to see the intricate branches responding to the sunlight. I imagine little leaf buds starting to develop and grow.

I feel dementia patients are waiting for the 'Eureka' moment of a cure, so they too can also blossom back into the wonderful person they once were, or at least no one will have to live in the darkness of Alzheimer's in the future.

#### Sylvia Wright, Lancashire

Sylvia's book Pure Art from the Heart is available from Amazon as a hardback, paperback or ebook.

# Letter: Keep busy, keep learning

I was diagnosed with mixed dementia in November 2023. Although I am in the early stage of my dementia, I find that going out and keeping busy helps.

I garden a lot, which helps me a lot. I also go to a dementia garden which is run locally, which I really enjoy.

We recently joined our local u3a (University of the Third Age) group, which I really enjoy as they do many activities that you can get involved in.

#### **David Matthews**

u3a has over 1,000 locally-run groups in the UK, bringing people together to enjoy learning – visit u3a.org.uk or call 020 8466 6139.

### Missing puzzle?

If you're looking for our regular anagramword puzzle from Pete Middleton, don't fret – we're taking a break this issue, but it will be back in the next magazine!

In the meantime, have you tried our Brain Workout puzzle packs?

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 today and sign
up with a monthly gift that helps
provide vital support to people
living with dementia.

## **Onset, diagnosis and now**

## Steve Kennedy, in Fermanagh, shares about life before he noticed his dementia symptoms, before diagnosis and since.



### Who were you before onset?

'Life was absolutely fantastic. I had the life of Riley, to be honest.

'I was working as a lorry driver – a job I started in my early 20s. I was a long-distance driver, spending six to eight weeks away from home and my wife Carmel.

'An average trip was between six and eight weeks and then I'd come back for a week. I was travelling all over, including the Middle East, North Africa and Scandinavia. I absolutely loved it.

'I learned several languages. My company was based in Germany, and I was fluent in German and had good French, Spanish and a bit of Italian.

'At home, we ran a dog kennel and

also bred dogs. Carmel managed most of this because I was away so much and took part in dog shows.'

## Who were you before diagnosis?

'In my mid-50s, when I was back home, Carmel spotted my concentration wasn't good.

'She said I wasn't taking interest in conversations. If we sat down to watch TV, I would stare at the screen not taking anything in.

'I hadn't noticed all this and just put it down to tiredness.

'But when my company got involved and said I wasn't keeping records correctly, I started taking it more seriously. I couldn't work out why I was making mistakes when I knew my job inside-out.

'The more I tried to concentrate, the harder it became.

'The first time I saw a doctor, they just put it down to my age and lifestyle.

'But my problems progressed and I ended up going back to the doctor two more times. After the third visit, I was referred straight to a consultant.

'Alzheimer's disease wasn't what we expected – I don't know what we did expect but not this.'

#### Who are you now?

'I was floored by the diagnosis and went to a dark place.

'But gradually, over 12 months, I rebuilt my outlook.

'Going to peer support group helped me. They built me up and empowered me. Carmel has been absolutely golden.

'I've become a dementia activist and I'm involved with dementia research. I want to get my name and my voice out there. I want to raise awareness about the realities of dementia and advocate for people with young-onset dementia.

'I stay busy at home. I do some farming – we keep a few cattle and we're still breeding dogs. I'm also a judge for the Irish Kennel Club. I love walking in the mountains. It keeps my head clear.

'Carmel and I have planned ahead for future, so now we can just enjoy life.

'People are always shocked when I tell them dementia is the best thing that ever happened to me.

'But it's given me a wonderful but different lifestyle. Without it, I'd still be doing my job and away from home.'

### **Grasmere Days**



A new book, designed with and for people living with dementia, celebrates the life and writings of Dorothy Wordsworth.

Dorothy Wordsworth's Grasmere Days has a narrative that's easy to follow, with beautiful photos and illustrations to help prompt curiosity, imagination and conversation.

Writer Sarah Lawrance says, 'We've involved people living with dementia throughout the development process, helping ensure our books are accessible, engaging and spark conversation.

'With a story on every page, people can have an enjoyable and meaningful reading experience that may have been lost to them.

'Some readers may not have heard of Dorothy Wordsworth, but she was an incredible woman who captured in her letters and journals so much that is completely relatable.'

Dorothy was sister of the Romantic poet William Wordsworth, and her journals capture the Lake District landscape in all seasons and weathers.

This is the second book from Open Ended Books, an initiative from the creative ageing charity Equal Arts. The first was Bewick Tales, stories from the life and work of Thomas Bewick. Both titles from Open Ended Books are available at £15.99 each from Equal Arts – see equalarts.org.uk/shop or call 0191 261 1619.

# Young-onset dementia conference

The third annual U&ME young-onset dementia conference takes place at Elland Road Stadium in Leeds on 14 October.

Organised by North Yorkshire charity Dementia Forward, the conference theme this year is Creating Change – Shaping the Future of Young Onset Dementia.

It will bring together people living with young-onset dementia, professionals, researchers and others for sessions with speakers, interactive workshops and a marketplace showcasing services.

Tickets are £50 – to find out more, call **01765 601224** or email **info@dementiaforward.org.uk** 



### **3NDWG** webinars

Webinars from the 3 Nations Dementia Working Group (3NDWG) cover anything from positivity to support for carers, and they're all led by people with lived experience.

3NDWG is a friendly group of people diagnosed with dementia from across England, Wales, and Northern Ireland who want to make a difference. Their voices are not only heard but actively sought out by policymakers, researchers and service providers. To register for upcoming webinars and watch previous sessions, and to join 3NDWG, visit

### Research Network



Our Research Network volunteers bring insight from their lived experience to help make sure dementia research is as meaningful as possible.

Volunteers from the network are involved in our decisions about what research to fund, and they help our researchers understand how they can have the biggest impact on people's lives.

This summer, the Research Network reviewed 171 research proposals, so we could shortlist 63 to invite to submit a full application.

Network volunteers have been supporting researchers to develop these applications, and they'll also help us review them at the next stage. Sound interesting? To find out more about the Research Network, email Claire Stockwell-Lance at ResearchNetwork@alzheimers.org.uk

### **Share**

Share your views, feedback and news – email **magazine@alzheimers.org.uk** or write to the address on page 2. We can consider contributions received by 5 September for the October/November issue (wording may be edited).

alzheimers.org.uk/3NDWG

## Feeling unheard

Dealing with how it feels when you have dementia and people aren't listening to you.

e all need to feel heard. It helps us feel safe, connected and valued. It also supports our sense of who we are.

That doesn't change with a dementia diagnosis. If someone isn't listening to you, it can lead to your needs not being understood or met properly.

Not feeling heard or respected could make you feel like you don't matter. It may affect your confidence. You might feel like you don't have control over your life or what happens to you.

This can bring up difficult emotions, such as anxiety, fear, panic, sadness, grief, frustration and anger. It can also affect your relationships.

### **Calm and confident**

If you start feeling difficult emotions, try to do something that calms you and brings you peace.

For some people, this could be meditation or listening to music. For others, it's gardening or going for a walk. What could work for you?

Keep doing things that help you feel confident and relaxed. Perhaps you need to adapt how you do these as time goes on. That's OK – the important thing is to still do things that you enjoy.

#### **Keep talking**

Tell people how you feel and try not to become isolated.

Even with the best intentions, people can sometimes take over or assume they know what's best. Maybe they're struggling to adapt to the situation, and they're trying to help in the only way they know how.

You're not responsible for how others treat you. But tell people what you need from them, and how important it is that you feel heard by them.

### **Your tips**

'I have experienced people not listening to me or overlooking something I've said, or acting as if I've said nothing.

'It makes me want to ask them, "Have you not heard what I've said, or do you just not understand my meaning? Or do you just not care?"

'I write down my feelings and thoughts, what it's like emotionally, in simple direct words of description and explanation.

'When the hurt feelings subside, I use what I've written in prose to write a short poem. This relieves my bad feelings and gives me something creative to do – a win-win!

'Later, it helps me to put it into spoken language. This started two years ago, when I wrote an emotional poem describing my first experience of having been diagnosed with this horrible disease.' **David Joseph** 

'A cup of tea always sorts me out and everyone in my community knows that. Any signs of distress, even if mild, and a cup of tea arrives. Often, we have a good laugh about it, but I am very grateful.

'I would want the person upsetting me to know that they were upsetting me. Then I would want to help them understand why and learn from it to do better next time, and toward others.

'It would be good if someone else around them who understands could intervene by showing a better way of responding – hoping to instruct by example but, if necessary, actually saying something to explain.' **Jennifer Bute**  People affected by dementia share ideas and advice on our Dementia Support Forum – visit **forum.alzheimers.org.uk** 

See alzheimers.org.uk/publications or call 0300 303 5933 for our:

- Your relationships (1507) booklet for people with dementia.
- Communicating (500) factsheet for carers about communicating with a person who has dementia.

## **Opinion:**

## **Ask for help**

Michael Booth, in County Durham, wants more people with dementia to find out what help they can get from diagnosis onwards.

he more I talk about reaching out for help, the more people get back to say they found support they never knew was there.

Yes, some areas have more services than others and often people don't signpost you to what is there. That isn't how it should be.

However, don't wait for help to come to you. Have a look, speak to people and find out what's there. Maybe there's something local that isn't designed for dementia but could still be great.

It could mean you get the exercise you need or get out of the house a little bit more. Or that you have support come into your home, or somebody to talk to or to help with your finances.

### Learning to speak up

My mum had Alzheimer's and I was caring for her for 10 years. Like most people at that stage, we kept it quiet. We took care of things ourselves. I didn't realise how much support was out there until later on. By that time, it was a bit late. But that's where I learned to speak up.

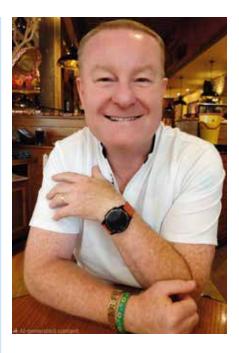
When I was diagnosed with young-onset Alzheimer's, I lost my job and my driver's license within the same week. There's a lot to deal with and a lot of fear.

When you have dementia, you can find ways to live with it. When you get to the point where you can't do that yourself, hopefully whoever's caring for you knows what you want and how you want to be cared for.

You need to have been open about it and spoken about it.

#### What do you need?

Sometimes speaking up is very difficult for people living with dementia.



In British culture, we don't tell people our problems – we'll struggle on because that's what we've done before. In some communities, people tend to keep things within their family.

But it doesn't matter what type of person you are, we all need support.

Whether you need something now or you'll need it in the future, the more you let people know your concerns, the more support you can get. Be specific about what you need.

#### Take control

Within your local area, there might be a café that you've never realised supports people with dementia. Some supermarkets do quiet times or can assign somebody to walk around and help you.

Some of the best resources I've got are down South – they're miles away but we're able to talk online. If you're not technologically inclined, is there somebody who can help you with that?

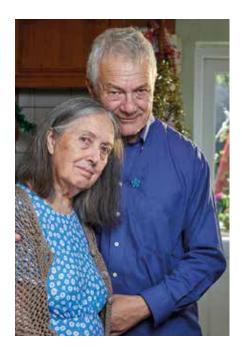
Meet other people with dementia. We're not the only people going through this, so there will always be somebody there who can help and guide us. I've been able to put people in touch with others who can help them with things like benefits.

Find those key people who can help you – take control and seek them out.

To find support near you, visit alzheimers.org.uk/dementiadirectory or call 0333 150 3456 for personalised advice.

## **Driving change**

Del, in Essex, shares how he and his partner Margaret are helping to educate bus drivers about dementia.



was a bus driver for 19 years and several times, I recall seeing passengers who obviously had dementia and were struggling to work out where they were or what was happening.

For instance, a lady used to regularly get on the bus in Billericay at 9pm in the evening with her shopping trolley. I had to spend time persuading her it was the evening, not 9am.

#### Random idea

It was quite random how the leaflet came about. I saw an advert about an older man on a bus at the end of a journey. The driver tells him to get off and he's not got a clue where he is.

I thought to myself, 'That could easily happen.' I also thought about it happening to my partner Margaret, who has dementia.

It's hard as a driver. You haven't got much time, you've got a timetable to stick to and it's difficult to know what to do with someone who's very confused.

### **Getting involved**

We like to get involved with Alzheimer's Society activities when we can.

We were involved in a chat about how local businesses can be more helpful to people with dementia, so I suggested bus companies. I mentioned the advert and talked about my experience as a driver, and it went from there.

Michelle Burrows, Service User Involvement Officer at the Society, got in touch with First Bus – the company I used to drive for – and one thing led to another. The result is a leaflet to help drivers recognise the signs of dementia and offer support.

Both Margaret and I contributed, and we're proud to see how well it has turned out. It's amazing what's come from a little chat!

The leaflet has advice on dealing with lost or confused passengers. It tells drivers to follow procedures, which is great because it means they can't just abandon someone. If it only helps one person that would be a great thing.

I'd love to see advice like this rolled out – it could even be used for local taxi firms, for example.

#### Sense of achievement

I'd encourage people to speak out and get involved with making a change. Not only will you help other people, but you'll also do yourself the world of good.

Margaret is now bed bound, so as her carer I'm at home most of the time. Contributing to the leaflet and doing things like this is great. It gives me purpose.

If you can use your knowledge to help others, it will make you feel good and help make a change to society, even if it's tiny.

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

Could you do something that creates change for others? For ideas, see alzheimers.org.uk/get-involved or call 0330 333 0804.

## Channel challenge

## Lindsey Walke, in Plymouth, shares her experience of swimming the English Channel to help fight dementia.

was a club swimmer when I was growing up. I wasn't massively competitive, but I got to a decent standard and I've continued ever since.

Swimming the Channel was a childhood dream of mine.

The idea to do it in memory of my fabulous nan came from friends' encouragement and chatting with people who have done it or who want to do it.

### Celebrating my nan

My nan Margaret was a second mum to me. Somebody I could always rely on.

I would cry on her shoulder, laugh with her, go to her for a good meal, everything. She was absolutely brilliant. Very strong minded, independent and very modern thinking for her time.

She was diagnosed with Alzheimer's disease and passed away in 2017.

I knew if I did the Channel swim, it had to be for a cause close to my heart. So that's why I chose Alzheimer's Society.

### Intense training

I trained for about 18 months. I swam in a pool but also did long hours of sea training to get used to the cold water.

This included doing the Eddystone Swim, from the Eddystone Lighthouse to Plymouth Hoe, which is about 14 miles.

When the day finally arrived to take on the Channel, I was excited but there were lots of nerves too.

My nan would have been extremely happy to see me, but she would have thought I was nuts. She was a casual swimmer, nothing like this.





#### Never give up

Once I started swimming, my nerves settled.

I'd never have given up, even though it got hard. I thought of my nan and about everyone who sponsored me – I didn't want to let anyone down.

Every hour, I ate. You're not allowed to touch the safety boat or anybody, so you tread water.

My friends were on the boat and kept my spirits up with lots of clapping, cheering and encouragement. They instinctively knew when I was getting tired.

I saw cargo ships on the way, but apart from that it was just a vast space of water. That and my mates grinning at me from a boat. There were no dolphins or seals, but I did encounter loads of jellyfish halfway through. I couldn't move for seeing one or touching one. How I got away with such few stings surprises me.

There was also a point where whitebait fish surrounded me like a shroud. I was almost scooping them back with my hands.

### **High emotions**

The swim took 14 hours 20 minutes. Finishing was a relief and brilliant, of course, but I was also in shock. Loads of emotions were going went through my body and brain at the same time. My original fundraising target was £1,000 but I raised £3,150, which I was so pleased about.

If you're thinking about raising money, a good start is to think about what your passion is. It will keep you motivated.

I'd also recommend contacting the Society for support. They've been so helpful. I even had a message from Dame Suzi Leather, Chair of the Society's trustees, who read about my fundraising efforts.

Get a support team around you too. Having like-minded people who know how you feel and think and how to motivate you is important.

I think there's another physical challenge in me, but I need recover before I give it any serious thought!

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

## Research for everyone

Dementia research needs to involve all kinds of people in studies – including people from South Asian communities.



Dipali and her late father

Alzheimer's and vascular dementia,' says Jagdish in Manchester.

'I gave up my career to care and advocate for my dear Mum across all the fragmented services.

'Ensuring that Mum remained in her own home – safe – nearly broke me.'

Jagdish felt completely failed by services, from not having carers who could provide the right level and type of support, to her mum not receiving end of life care.

'I am channelling my grief and trauma into raising awareness of inequities and lack of inclusivity in dementia care for South Asian and other marginalised communities,' she says.

Research has a vital role to play in this

'Our lived experiences are central to research that informs policy and services.

'It's vital that our communities engage with research to improve services. Organisations also need to reach out to marginalised communities to raise awareness of the importance and impact of research.'

### **Bridging the gap**

Researchers need a range of people to take part in studies, otherwise we can't be sure their findings apply to everyone. But people from South Asian communities – among others – are underrepresented as participants.

Jaheeda Gangannagaripalli, Research Fellow at the University of Manchester, has been bridging this gap in her work.

While adapting an app that prevents falls for people with dementia – KOKU-LITE – Jaheeda reached out

to local South Asian communities to involve them.

'Unless we get input from them,' she says, 'we can't make the changes that take their preferences into account.'

That means making sure research is done in the right languages and in culturally appropriate ways.

It also means building trust, so people know it's worthwhile and safe to take part. Jaheeda underlines the importance of consistent contact in this, to share findings and more.

'We need to make that consistent, and researchers need the right training so that we're confident and approachable.'

#### **Motivated to volunteer**

At first, Dipali Das felt hesitant about taking part in research. However, her family's experiences of dementia – and wondering about her own risk of developing it – motivated her to volunteer.

Dipali's mother has young-onset dementia and her father, who died in 2023, had vascular dementia.

Dipali has gained a lot from taking part in dementia studies, and she's optimistic about how people will respond when they understand the benefits.

'It made me think more about my own health,' she says.

'It felt good to contribute to work that may hopefully help future generations.

'When people see opportunities to talk about it or get involved in research, I think it's welcome and embraced.

'It's very worthwhile.'

Find out how you can volunteer for all kinds of dementia research. Call **0333 150 3456** and ask for our Research Participation team, or email **joindementiaresearch@ alzheimers.org.uk** 

## Studying mealtimes

## How can good communication improve the experience of mealtimes for people with dementia?

hen she was working in care homes, speech and language therapist Rosey Meiring saw how challenging mealtimes could be for people with dementia.

'It can also be worrying for carers as well as friends and family, as they may be concerned about nutrition, and the social aspects of eating and drinking,' says Rosey, in west Wales.

But she also saw how carers can make mealtimes more enjoyable and beneficial if they're great communicators – even if they're not aware of their skills.

'For people living with dementia who need assistance at mealtimes, skilled carer communication is vital.'

#### Research journey

Inspired to find out more, Rosey has embarked on a PhD with funding from Alzheimer's Society.

'My aim is to find out what type of staff communication helps to avoid or resolve distress and problems around eating and drinking, as well as what is not helpful.'

Ultimately, Rosie wants her findings to improve training for care staff.

'My hope is that my research will add to the growing number of exciting studies helping us understand how interaction works with people living with dementia.

'What is it that carers do that helps people living with dementia to manage everyday tasks without getting distressed? And how can we pass those skills on?'

#### Video analysis

Rosey's work involves videoing mealtimes and studying the recordings using a method called 'conversation analysis'.

'This means I'll watch the videos lots of times and type everything I see and hear.

'From these transcripts, I'll look at what carers are doing with their words and actions that helps foster good mealtimes.'

Rosey, who's had a varied career in healthcare and education, heard about this type of research at a conference.

'A speech and language therapist talked about using videos of reallife interactions on inpatient wards and finding patterns that could help minimise distress in people with advanced dementia.

'That presenter is now my PhD supervisor and has helped me put together my team, who have supported me through the process of getting a research grant with Alzheimer's Society.'

#### **Brilliant opportunity**

Rosey describes her research as a 'real privilege'.

'Not only will it add to the body of evidence on how to improve quality of life for people living with dementia, but it is a fabulous development opportunity for me.

'I am hugely grateful to Alzheimer's Society and their supporters for their funding of my project and to the care homes, staff and residents who bravely allow themselves to be filmed.'



Your donation helps us to fund research into all forms of dementia, from prevention to breakthrough drug treatments. Donate online or call **0330 333 0804**.

## **Every person matters**

A Society service is breaking down barriers for Greater Manchester's South Asian communities. Antonia Kanczula reports on Sahara.

### **Quick read**

Sahara is a Society service reaching South Asian communities across the 10 boroughs of Greater Manchester.

It supports people affected by dementia and raises awareness about the condition.

Sahara's team members are from the communities that they support.

People supported by Sahara say it's improved their wellbeing and helped them feel less isolated.





he team are so bubbly, they're angels. When I see them, they lift me up,' says Jamila of her visits to the memory café at Rochdale's Golden Mosque.

'The first time I went, I was nervous about going in. But then I thought to myself, "If you don't go in, you'll never know."

'I'm there every month now and it makes me feel less isolated. They make you feel so special, so at ease. Every person matters.'

The memory café supporting Jamila on her dementia journey is one element of Sahara, launched by Alzheimer's Society in 2023.

Sahara, which means 'support' in Urdu, provides tailored dementia support to Greater Manchester's South Asian communities.

With a hugely dedicated team working across 10 boroughs, it's going from strength to strength.

### **Team from the community**

Sahara was initially made possible with the support of one of the Society's partners, explains Sue Clarke, Regional Manager for Greater Manchester. This helped consolidate pockets of work that were already happening.

'CBRE came to us and they were interested in supporting us with a big project to tackle health inequalities in Greater Manchester and reach out to communities.'

There was one key requirement from the outset – that the team running Sahara should be from South Asian communities.

'We knew we needed a team from the community, otherwise people would not want to reach into our service,' adds Sue.

Local Services Manager Sania Rehman has been with Sahara from the veru start.

She says getting it off the ground was a mammoth undertaking, and the team immersed themselves in research.

'We looked at existing services, finding out what was already available, from Alzheimer's Society and beyond, for the South Asian community and what worked and what didn't work,' says Sania.

'We officially started taking referrals in June 2023 and it's just never stopped since.'

#### **Stark barriers**

Reaching anyone affected by dementia, wherever they live, whatever community they're from can be hard enough.

But there are particular barriers for South Asian communities, explains Sania.

'Although things are going in a positive direction – younger generations are more willing to talk openly about dementia – our community can be very closed,' explains Sania.

Existing dementia services are often not designed to provide support in the right ways. For example, language can be a huge obstacle.

'English is not the first language of a lot of the older generation.

'Yes, there may be leaflets and booklets they can access in different languages like Urdu, Punjabi or Gujarati. However, lots of older people might not be able to read or,



depending on where they are on their dementia journey, they might have lost their ability to read.'

People with dementia may be labelled as 'mad' or 'possessed', says Sania.

'For example, if a person who has dementia with Lewy bodies experiences visual hallucination, it might be associated with possession. Also, with sundowning, this might be seen as a spiritual disease.'

Sadly, the combined impact of these barriers is stark. People from South Asian communities are less likely to receive an early diagnosis and to receive the specialised help and support they need.

#### Home and community

Sania's team now comprises three dementia advisers – Robana Naqvi, Nabeela Ali and Shagufta Majid – and they have a dedicated volunteer team.

They support people with dementia in their homes and communities, as well as reaching people who are worried about symptoms to help promote early diagnosis.

There are four main ways the team do this, explains Sania.

'First, we have GPs, healthcare professionals, referring into our services, including memory clinics.

'Then we have a focus on education and awareness. We do awareness sessions with lots of different groups and organisations. For example, we've been to prisons, places of worship and schools.

'We also have monthly memory cafés – there are three at the moment, in Rochdale, Stockport and Tameside – which are hugely popular.

'And then our most recent piece is supporting more people to participate in research. We've teamed up with Join Dementia Research to start the conversation about research and getting people involved.'

#### **Trust and learning**

In just two years, Sahara is clearly making a difference.

A recent evaluation shows that the people Sahara supports have a better understanding of dementia and improved wellbeing. They also feel less isolated and lonely.

Sue is in awe of the team's energy and dedication.

'This is a team that makes things happen,' she says.

'They have crossed those enduring boundaries, encouraged people to come forward and educated lots more about dementia. They have told people that it's OK to ask for help.'

Dementia Adviser Nabeela says the team's ability to build trust has been key.

'Having someone that speaks your language and understands your faith, your culture, your traditions, your values is hugely important.

'You've lifted a huge barrier to win their trust. It's a breakthrough. You're at a different level with them and they will share with you.'

Sania says, 'Recently someone said to me at a memory café, "I don't know what I would do with without this group. It feels like home, a safe space for me." I was so moved by her words,' says Sania.

As well as doing more in Greater Manchester, the team want to take what they've learned to other parts of the country. Their expertise is already being mined by colleagues elsewhere.

'We don't want to just stay still,' says Sania. 'We want to grow, we want to learn.'

For dementia information in languages other than English, visit alzheimers.org.uk/information-in-your-language

To speak to a dementia adviser in languages other than English and Welsh, call our Dementia Support Line **0333 150 3456** and say the English word for the language you'd like to use. We'll then arrange for an interpreter to call you back.

For Welsh language support, call **03300 947 400**.

Use our dementia directory to find local support services near you – see alzheimers.org.uk/dementiadirectory

## Safe and warm

As we look ahead to colder months, Heather Stephen reports on an energy partnership to help people affected by dementia boost safety and cut bills.

hen Kelly Willows called to see a couple living with dementia, she noticed they had no central heating. So the dementia adviser did some research and sourced grants for a boiler and heating system.

Kelly was visiting to carry out a care assessment and talk about the Priority Services Register. This free register helps vulnerable people if power, gas or water goes off in an emergency.

The advice emerged from training through a £1.9 million partnership between Alzheimer's Society and three UK gas distribution networks.

### **Quick read**

Our Gas Distribution Network partnership is helping people to save money on energy and stay safe at home.

This two-year
Alzheimer's Society
partnership is with
Cadent, Wales and West
Utilities and SGN.

It has provided special training for 800 staff and means we're reaching more people and giving energy advice.

Dementia Adviser Kelly says, 'The impact achieved by this amazing project has been tangible.' The Gas Distribution Network partnership aims to help people with dementia and their carers save money on energy and stay safe, but its scope has been far wider.

'The impact achieved by this amazing project has been tangible,' says Kelly.

'I am a massive champion of the partnership, which helps people with dementia maintain their independence and keep safe.'

### **Country wide**

People affected by dementia across England, Wales and Northern Ireland can benefit from the partnership, wherever they live.

Last May, Cadent – the UK's largest gas network – teamed up with the Society to add energy efficiency and gas safety advice to the support we provide.

Since then, two more networks have come on board – Wales and West Utilities and SGN.

The two-year partnership has provided funding for dementia advisers, so we can reach even more people.

It's also provided valuable training for 800 frontline staff on energy efficiency, getting help with bills, carbon monoxide awareness and the Priority Services Register.

It is hoped that 20,000 people with dementia will benefit, and we plan for this support to extend beyond the end of the partnership.

### **Deeper challenges**

Alina Stevens is one of our dementia advisers now sharing advice on energy safety and efficiency.

'Although my role is around energy use and safety,' says Alina, 'it can reveal much deeper challenges.

As an example, 'I was contacted by a gentleman who had heard about the partnership and wanted to find out about a locking cooker valve for his father.

'However, as our conversation progressed, he became tearful and it became clear there were multiple safeguarding concerns.'

After Alina arranged carer's and care needs assessments, they found that his dad qualified for fully funded 24-hour care. This was life-changing for both of them.

As part of her new role, Alina gives talks to community groups too. This reaches far more people than she would in one-to-one conversations.

'The partnership has given me







**Amanda Jones** 

confidence in public speaking, and I now have more understanding and awareness of the range of problems people face.'

Kelly Willows has gained a lot too. 'I have joined a peer network group which I wouldn't have done otherwise, I am hosting a visit from Cadent to one of our dementia cafés, and the training has been really useful in supporting my clients.'

### Lighten the load

Amanda Jones, Cadent's Safeguarding and Partnership Lead, has been a driving force.

She's delighted with the difference made by the partnership, made possible through Ofgem's Vulnerability and Carbon Monoxide Allowance.

'We identified people with dementia as high risk but as an organisation we don't have an opportunity to interact with these customers.

'That's why it was so important to link with a trusted organisation like Alzheimer's Society, who can develop relationships with people and signpost them to extra help.

'The project has helped a phenomenal number of people. It was so successful, we met with the other three gas distribution networks to take this across the UK.

'There is a lot of help out there, but people don't know about it. The beauty of the partnership is that we can get the right information to the right people.

'People with dementia and their carers have a lot on their plate. But I hope this project will lighten their load just a little and then I will have done my job.'



# Energy: what can help?

- Act early check your boiler is working before the cold weather sets in.
- Small changes to be more energy efficient can make a big difference to comfort and cost.
- We can help you find local grants for energy costs – call our Dementia Support Line on 0333 150 3456.
- Carbon monoxide alarms save lives – is yours fitted and working?
- The Priority Services Register is free and helps when services are disrupted – see thepsr.co.uk or call our Dementia Support Line.

Call the Dementia Support Line on **0333 150 3456** to find out how our Gas Distribution Network partnership can help you with gas safety, the Priority Services Register, energy efficiency, getting your boiler checked and more.

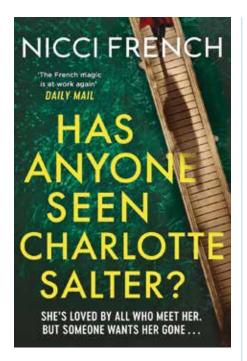
For leaflets on energy efficiency, the Priority Services Register and carbon monoxide safety, produced through the partnership, see alzheimers.org.uk/qdn-advice

For our Keeping safe at home (1502) booklet, visit alzheimers.org.uk/publications or call 0300 303 5933.

## **Book group:**

## Has anyone seen Charlotte Salter?

We read a thriller about a family with a long-disappeared mother and a father whose dementia is getting worse.



Has Anyone Seen Charlotte Salter? by Nicci French (Simon and Schuster, 2024), 560 pages, £9.99, ISBN: 9781398524118. Also available as an ebook and audiobook.

icci French are a wife-and
-husband team – Nicci
Gerrard and Stephen French
- with a string of best-selling
thrillers to their combined name.

Nicci's father had dementia, and his final hospital stay inspired John's Campaign. This fights for families' involvement in a person's care in hospitals and other settings.

We were intrigued by Has Anyone Seen Charlotte Salter? because one of its central characters has dementia.

Meghan Higgins says, 'It begins in the 1990s, setting the scene of

Charlotte's disappearance and the death of Duncan Ackerley.

'We're reintroduced to their families over 30 years later, where Alec Salter has developed dementia and his family are navigating his move into a care home setting.

'At the same time, the Ackerley children are hosting a podcast to explore the two tragedies and uncover the truth of what happened all those years ago.'

### **Telling the story**

Some of our reviewers loved how this story was told.

'From the moment I opened this book I was hooked, and by the time I turned the last page I was left spiralling,' says Ene Ogbole.

'At the point when one of my favourite characters was being hinted at as the suspect behind Charlotte's disappearance, I was shaken! I literally gasped out loud and my eyes welled up.'

Kym in London says, 'I was immediately hooked by this book and read it in two sittings.'

As well as liking how the prologue and afterword bookended the story, Kym thought the two time periods were presented well.

'I much preferred the story being in two halves rather than jumping backwards and forwards in every chapter,' she says.

Toto2 on Dementia Support Forum agrees, 'The storyline is amazing, as are all of Nicci French's books.

'Plenty of can't-put-down chapters and some very sad events, and a very clever detective who will not rest until she has the answers she wants.'

Not everyone enjoyed the book's

structure or style. Hillary Mead, Patricia in Northumberland and Maggie Clark all thought it was far too long.

Although Hillary 'likes a good murder', she prefers classic mysteries such as those by Agatha Christie.

'The end is too brief,' adds Patricia, 'with an unbelievable summary of how the crimes were dealt with and whether justice was actually carried out.'

However, after what she describes a 'never-ending storyline', Maggie's final rating wasn't as low as she'd expected.

'I persevered to the predictable end and admitted it was five out of 10!'

#### Portraual of dementia

Our readers had wide-ranging views about how the book portrayed dementia.

Toto 2 says, 'The fact that Alec ended up with dementia, and was moved from the family home into a nursing home, was not given as much attention or detail that it deserved or I expected it to.'

Hillary, who has vascular dementia and Alzheimer's, agrees, 'I thought there'd be far more about dementia in it. The references to it didn't help anyone with or anyone caring for.'

Patricia says, 'The story around the health and welfare of this character left me thinking that he might as well have had a broken fingernail.

'There appeared to be no understanding or empathy from his family, and I thought it was a horrendous way in which his home was stripped and disposed of whilst he was still living there and when he was placed in the care home.'

Although Marion Chapman didn't warm to Alec's character, she thought his having dementia had value.

'His developing dementia and subsequent behaviour was not as impactful as if he had been a more engaging, likeable person,' she says.

'However, I am always in favour of dementia becoming a more everyday part of novels, TV etc. Hopefully this will touch some people who are not part of this world, and make them think and have compassion for those affected by dementia.'

For Meghan, dementia played a more meaningful role within the story.

'Alec's dementia is used as a tool to add a complication to the plot and further the mustery,' she says.

Meghan also notes the resentful inner monologue of some characters towards Alec.

'Whilst this can be quite challenging to read, I do think there are families that might be able to relate to navigating supporting a family member with dementia, with whom they do not have a positive relationship.'

Kym found Alec's portrayal to be realistic and sensitive, and the book's theme of loss thought provoking.

'The ambiguous loss of the main family when their mother disappears, and not knowing what has happened or to have any finality or a chance to say goodbye, really resonated with me,' she says.

'It has so many parallels with watching a relative with dementia slowly fade away. There are no answers, no reasons to provide a clear answer to, "Why has this happened to us, how did this happen, where have they gone?"

#### **Thriller readers**

Overall, Marion says this book is a 'well-crafted thriller'.

'Nicci Gerrard's What Dementia Teaches Us about Love is a much better and personal take on dementia, love and family ties,' she adds. 'But as a thriller this is a very good read.'

'I will absolutely be recommending this book to my other book club members at my workplace,' says Kym, 'and hope that they enjoy it as much as I did.'

Toto2 agrees, 'I would advise anyone who loves reading to add this to their list. It had me shocked, surprised and sad at the same time.'

Meghan is more circumspect.

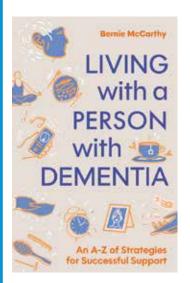
'I might recommend this book to avid thriller readers, who like twists and turns in their stories,' she says.

'It might be a challenging read for some, considering the framing of the impacts of dementia. However, someone with experience of the complications of caring for an estranged family member might find it quite validating.'

Ene adds, 'As for the motive behind Charlotte's disappearance? I actually laughed, not because it was funny, but because it was so absurdly human.

'There's more to it, of course, but I'll leave that for interested readers to uncover...'

## **Next time**



For our next book group, we invite you to read Living with a Person with Dementia: An A-Z of Strategies for Successful Support by Bernie McCarthy (Jessica Kingsley, 2025), 224 pages, £14.99, ISBN: 9781839973826. Also available as an ebook.

Tell us what you think of this book, which aims to help carers understand dementia and provides an A to Z of issues that come up.

Please email **magazine@ alzheimers.org.uk** or write to the address on page 2 by the end of 4 September so we can share your comments in a future article.

## Book giveaway

We have five copies of Living with a Person with Dementia to give away – email **magazine@alzheimers.org.uk** or write to the address on page 2 by the end of 14 August quoting 'Living' for a chance to win (see page 39 for terms and conditions).

# **Snacks and mealtimes**

## People affected by dementia try out products designed to help with eating and drinking.



ementia Voice local groups meet regularly to influence what the Society and other organisations do. Through them, people share valuable feedback and guidance based on their lived experiences.

Norwich's group is no exception, and we got their opinions on products designed to help drinking and eating, all available from our shop.



### **Droplet Reminder**

The Droplet Reminder hydration set includes a mug and tumbler that fit onto an electronic base. Voice messages and lights prompt you to drink if you haven't lifted the cup for a set time.

You can use pre-set messages or record your own. You can also choose for reminders to come on after 20, 40 or 60 minutes – whatever would best help you to stay hydrated.

'That would have been helpful for my mum,' said Jan.

Carol agreed, 'Fred makes a coffee and forgets to drink it.'

Some people would need the settings done for them the first time it's used. The base takes three AAA batteries, which you need to buy separately.

Michelle thought an option to charge the base would be helpful, though it has an alert for when batteries need to be replaced.

The set includes a lid with a discreet spout and a hole for a straw.

Tina liked that the mug and tumbler didn't feel heavy – something her dad struggles with. The group suggested a two-handled mug as an idea for future models.

Not everyone heard the reminders going off in the hubbub of the session, though their volume can be adjusted.

Roger noted, 'You would hear it if it's right by your chair.'



### Rosa trays and mugs

Lightweight and easy to handle, Rosa mugs and trays fit together to hold a snack and drink in one.

The mugs are two handled and their cheerful cat, dog and lilac designs match the trays. You can buy them separately or as a set.

'I'm very impressed with that,' said Carol. She also thought the price for the mug and tray set was good value.

Jan liked the mugs, but thought the tray could work better on a side table than on your lap. 'My mum would try to cross her legs!'

Asked if he'd consider using the set, Fred said, 'Oh yes, I think so.'

There are also two clear lids for the mug – one with a hole and another with a spout – that you can get in single or double packs.

Tina was pleased that the discreet 'dignity' mug lid, which has a hole and no spout, can be used either for sipping or with a straw.

Jan thought options with plainer designs would be good. The group was enthusiastic about a possible new forgetme-not pattern for Rosa mugs and trays.

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

- Droplet Reminder hydration set – £29.95.
- Rosa two handled mug (dog, cat or lilac) – £11.99.
- Rosa tray (dog, cat or lilac)
   £13.99.
- Rosa mug and tray set (dog, cat or lilac) – £22.99.
- Rosa dignity mug lid
   £3.99 for one or £8.99 for a pack of two.
- Rosa spouted mug lid

   £3.99 for one or £8.99

   for a pack of two.
- Pashmina Style Clothes Protector (dotted burgundy, navy or grey)
   £16.99.
- Cross Scarf Clothes
   Protector (navy blue)
   £15.99.

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

He was followed by Ian, Graham and Fred, all of whom found it comfortable. Fred thought it 'looks a bit like a waistcoat'.

The group was impressed with the appearance of both protectors, especially when compared to more usual napkin and tabard styles.

'You could take one to use at a restaurant,' said Jan.

"... and not feel embarrassed," added Carol, who was also pleased to confirm that they're machine washable.

Jan liked their prices, though Tina suggested providing them in packs of two.

'You'd want a couple,' she noted.
'One to use and one in the wash.'





### **Clothes protectors**

We showed the group two styles of clothes protector that are designed to be unobtrusive while keeping clothes clean. Both are made of soft fabric with absorbent layers, waterproof linings and velcro fastenings.

Carol modelled the Pashmina Style Clothes Protector, an elegant scarf that fastens behind the neck.

She described it as 'ladylike', and Tina liked that there was a choice of colours for the dotted design – burgundy, navy or grey.

Danny was first to try on the Cross Scarf Clothes Protector, which fastens at the front in a simple, smart style. For our Eating and drinking (511) factsheet, please see alzheimers.org.uk/publications or call **0300 303 5933**.

# One day at a time

Dalwinder has had to learn quickly while caring for two parents with dementia. Antonia Kanczula meets a man focused on what he can do.



### 66

## When it doesn't affect you, you don't really pay much attention to it do you? I didn't really know much about it at all.

efore both his parents were diagnosed with dementia, Dalwinder in west London, didn't know a lot about the condition.

'When it doesn't affect you, you don't really pay much attention to it do you? I didn't really know much about it at all.'

But after supporting both his parents, Dalwinder says that being a carer has become all-consuming.

'I wouldn't wish dementia on anyone. It's so hard watching a person go downhill like this.'

#### Life and soul

These days Dalwinder's dad Gurdev, 96, is quiet and withdrawn. He doesn't often leave the home that he and his son share.

But he used to be the life and soul, always on the move, says Dalwinder.

'Before all this, I mean, he wouldn't let you talk. Now, he just wants peace and quiet.

'He enjoyed walking eight to 10 miles a day and visiting people he knew.

'I'd often get calls from friends saying, "What's your dad doing in Harrow?" which is miles away.

'Sometimes you wouldn't see him until he came home for dinner at six or seven in the evening.'

### **Busy and sociable**

Born in the Punjab in northwestern India, Gurdev moved to East Africa to work in the 1950s, working in customs.

He eventually settled with his wife Ranjit in Tanzania, where Dalwinder and his four sisters were born.

The family moved to the UK in 1973 because of Gurdev's work.

Dalwinder, the couple's second youngest child, says theirs was a busy and sociable home.

'My mum was the centre of the family. She was always on the move. She was tiny compared to Dad but a powerhouse.

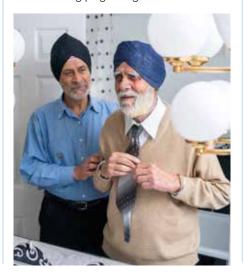
'She was funny, chatty and always very jovial. She loved hosting family celebrations and I have lots of memories of big parties for new year, birthdays and weddings.'

'My parents were married for over 70 years and did everything together, including watching lots of EastEnders. I used to say to my friends, "If you ever miss an episode, just give me a call, I'll give you a Punjabi version!"

#### **Pandemic impact**

Dalwinder says the Covid pandemic was a difficult time for his sociable family. It was also a turning point for his parents' health.

'We followed the rules. We all stayed inside a lot more, which meant that we were interacting less and Dad couldn't stay physically fit with his walks.'



Dalwinder and his sisters also noticed subtle changes in both Ranjit and Gurdev.

'Mum's situation got worse before Dad's – she was having a lot of problems, one thing after another.'

'She couldn't pick something up with a spoon and put it in her mouth. It was like she was aiming for her ears.

'I gave her a glass of orange juice once and she just dropped it straight on the floor, smashing the glass.'

Deprived of his treasured walks, Gurdev's physical strength declined and when he did start going out more, the family noticed his walking had changed.

'He couldn't seem to walk in a straight line and was struggling to go any distance.'

Dalwinder also noticed his dad having problems with his memory.

'When we were sitting in traffic, he would say "that car's always in front of us!" pointing at the car in front.

'But he would forget that we hadn't moved and that it was the same car for that reason.'

### **Dementia diagnosis**

Worried about his mum's health, Dalwinder took her to the family GP, who then referred her to a memory clinic.

Ranjit spoke mainly in Punjabi, so Dalwinder had to explain everything the healthcare professionals were saying.

Ranjit was diagnosed with vascular dementia. Just a few months later, at the same memory clinic and with the same specialist, Gurdev was diagnosed with mixed Alzheimer's disease and vascular dementia.

It was an overwhelming and confusing time.

'They handed us loads of printed information at the memory clinic and we tried to make sense of it all.'

Sadly, in September 2022, only three months after receiving her diagnosis, Ranjit died following a bleed on her brain.

Adjusting to life without the family's matriarch has been incredibly difficult, says Dalwinder. Grief has also noticeably affected his dad's dementia symptoms.

'He feels intense loneliness, but he forgets or gets confused about her not being there. He often cries and asks me if Mum has passed away.

'We think his grief has made his dementia much worse.'

### **Help and support**

Dalwinder's once busy life and his career in freight forwarding are now paused while he cares full-time for his dad.

'i've got to watch Dad's every step now. It's becoming increasingly difficult to ensure he gets everything he needs.'

Apart from help from three sisters who live not too far away, Dalwinder



He used to have a great appetite too, but he doesn't eat much now and has become really fussy, frequently refusing the things I cook.

cares for his dad's every need. This includes everything from getting dressed to taking his medication and going to appointments.

Dalwinder feels a sense of duty after his parents' care in bringing him up. However, he acknowledges that it's a 'challenging, tiring and lonely' existence at times.

A lifeline came when he first reached out to Alzheimer's Society after seeing a TV advert.

He describes Gurdev's dementia adviser Madhuri as a 'gem'.

'She's really helpful. I mean if I need any help and advice, I'll always ring her and she'll point me in the right direction.

'For example, she's helped me with voice activation tech – putting

speakers around the house.

'At one point Dad was frightened of getting in the bath. Madhuri explained about the fear of falling and how dementia has affected his perception of things and we managed to work out a solution.'

Madhuri is also an emotional support. 'She's really good with him and he loves seeing her.'

Extra respite also came when Dalwinder started taking his dad to monthly peer support meetings at the Sikh temple.

'They make it fun, with quizzes, general conversation and a tasty meal.

'I got to meet other carers and Dad gets to talk about old times with other people from the Sikh community who have dementia. Suddenly, all the old memories from decades ago come flooding back to him.'

#### Life on hold

Sadly, it's rare for Gurdev to leave the house now.

'The big challenges we have at the moment are getting Dad up and dressed. He used to be so active and now he just wants to stay in and sleep.

'He used to have a great appetite too, but he doesn't eat much now and



has become really fussy, frequently refusing the things I cook.'

Dalwinder admits his own wellbeing has been affected by being a full-time carer. It's hard to find the time and headspace to look after himself.

All his passions, such as cycling and travel, are on ice.

'I don't get any exercise, apart from gardening and doing chores around the house.'

But he tries to stay upbeat, taking energy from his wider family, friends and a new relationship.

He also has some sacred time to himself at the end of an exhausting day.

'To me, what is relaxing is watching a movie. When Dad has gone to bed and I've done all my chores and spoken with my girlfriend, I find sitting in front of the telly is really relaxing.

'You start getting into something and you forget the world. You just engross yourself in that film and you've forgotten everything.'

#### No shame

Having previously not known anything about dementia, Dalwinder's experience as a carer means he has valuable advice for other people. 'Dementia's still a taboo, particularly in Asian culture but really, what is there to be ashamed of?

'Being open and having honest conversations is the way forward because only then can you access help and support.'

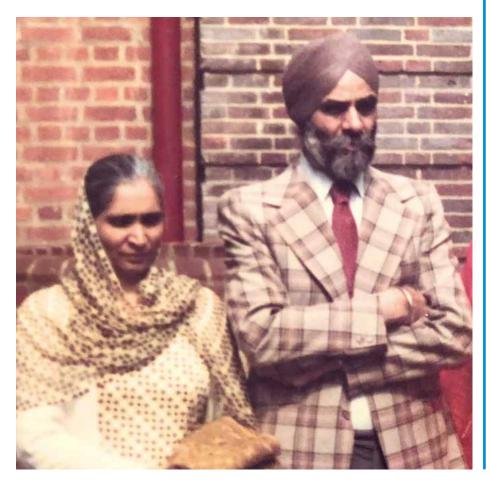
Dalwinder's philosophy is to take every day as it comes, saying, 'That's all I can do.

'My friend sent me something the other day that I thought was quite important.

'It was a motivational quote that said, "Hope is the power that gives the person confidence to step out and try."

'Well, we all live in hope. That's the bottom line.'

For Caring for a person with dementia: A practical guide (600) and our Grief, loss and bereavement (507) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933.



To find support near you, visit alzheimers.org.uk/dementiadirectory or call 0333 150 3456 for personalised advice.

## **Moving within England**

'My dad lives alone in another part of England and needs a care home, but I want him to move near me. Which local authority do I contact to arrange this?'



hether you need to involve a local authority depends on your dad's finances and who's making decisions.

#### **Making decisions**

If your dad has mental capacity, where to move is his decision to make.

If he lacks capacity for this, then the decision must be made in your dad's best interests. This should take account of his past, present and future wishes. He should still be involved as much as possible.

For you to make this decision, you'd need the legal power to act on his behalf.

In England, this is usually through a lasting power of attorney (LPA) for health and welfare. You'd also need an LPA for property and finance or deputyship to access his money to pay for care.

#### **Accessible funds**

Because your dad is in England, he'll be considered a 'self-funder' if he has more than £23,250 in savings and assets.

If these funds are accessible, your dad's move can be arranged directly with a care home that's closer to you.

You don't usually need to involve his local authority unless your dad lacks capacity and you don't have the legal power to act on his behalf.

After he's moved, if his funds then fall to £23,250, contact the local authority in his new area about future funding.

### **Tied-up funds**

Some self-funders can't access their funds because these are tied up in their home.

If that's your dad, you can ask his current local authority for a '12-week property disregard' and a 'deferred payment agreement' (DPA).

A 12-week property disregard means that, when the local authority assesses your dad's finances, it will temporarily ignore the value of his home.

The DPA provides funding as a loan, which would be repaid to the local authority after his property is sold.

A DPA should be in place by the end of the 12-week disregard. These can be complex, so ask the local authority for advice. You can find information about DPAs at moneyhelper.org.uk

### **Not self-funding**

If your dad isn't a self-funder, or if his savings and assets are only slightly over the limit, ask his current local authority for a care assessment and a financial assessment.

The authority must allow for care homes outside its area, provided the home has availability, can meet your dad's needs, is within budget, and is willing to work with his current local authority.

### If authorities disagree

If there's a disagreement between local authorities about who is responsible for funding your dad's care, they should resolve that between themselves.

If no local authority is already meeting a person's needs, the authority where they currently live must take responsibility until the dispute is resolved. Care should not be delayed because of a funding dispute.

Paying for care is different in Wales, Northern Ireland and England. See **alzheimers.org.uk/ publications** or call **0300 303 5933** for our:

- Paying for care and support in England (532) factsheet.
- Paying for care and support in Wales (W532) factsheet.
- Paying for care and support in Northern Ireland (NI532) factsheet.
- Choosing a care home for a person with dementia (690) booklet.

## To help or not

## Readers share advice about deciding whether to help a family member or friend who has dementia to do something.

eciding whether to step in to help a person with dementia to do something can be tricky.

We asked readers and members of our Dementia Support Forum for their advice and experiences.

'In my experience, if you see someone struggling and it is upsetting them, offer help or suggest you do it together.

'This is fine if you have no time constraints of course. Sometimes it's not always practical to give someone all the time they need.

'I suggest offering help immediately on these occasions and speed up the task, so an important appointment can be met with less frustration.' **SJaay** 

'Everyone with dementia is different and those closest know the person best. There are no 'rights or wrongs' here, and what works one day may have unexpected consequences the next day.

'So the answer is, "It depends."

### Jaded'n'faded

'I let my other half try if it will not endanger himself. Otherwise we do a lot of, "Shall we do this together?" This could be fun or interesting if we both work together.

'The word "you" has almost disappeared from my vocabulary. It seems to work for us, using a shared approach, however slow it might make things.' **Pili45** 

'I used to feel a bit mean listening to mother-in-law chunnering to herself, "I don't know what I'm doing," as she took forever to make a cup of tea and find the biscuits and cakes.

'It was also useful to gauge what kind of a day she was having and how she changed over time.' **sheepfield**  'Brother was main carer and thought he was being "good" in doing most things for Mum. Yet all he was actually doing was taking away the little bit of independence she did have.

'I always supervised things first to see if Mum was able to manage and, if she could, I would leave her to it. She had a sense of achievement then and was happy that she could still do things.

'Trying to "take over" just seems to take away the little pleasures they have in being able to still do something they were used to doing. Saying "I will do that for you" sounds a bit demeaning unless it is something you know they cannot do.

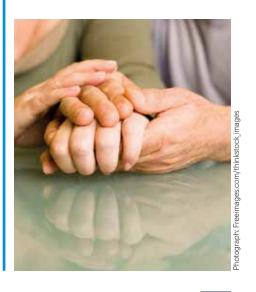
'Give them a chance and, if they cannot manage, then step in. That is what I used to do anyway, and it worked with certain things.' **Toto2** 

Visit **forum.alzheimers.org.uk** to read more and join our Dementia Support Forum.

For our Understanding and supporting a person with dementia (524) factsheet, visit alzheimers.org.uk/publications or call 0300 303 5933.

### Next time: Being prepared

Do you have any advice about how to be prepared enough for a sudden change or difficult situation? Email **magazine@alzheimers.org.uk** or write to the address on p2 by the end of 4 September.



## **Noticeboard**

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

### Letters

### 'I'm losing her, but | 'Memory Mary' I'm holding on'

My life is on hold. As well as caring for my mum, who was diagnosed with Alzheimer's disease during the pandemic, I also care for my sister, who has disabilities.

I can't travel, work full-time, go out or do things independently on a whim. I don't have space for a relationship.

On the flipside of all the sacrifices I've made, looking after my mum and my sister is so rewarding too.

I love them so much and our bond is unbreakable. Every day, I get to share moments of sheer joy with them.

When Mum appreciates something that I do for her and says, 'Thank you', I see the love in her eyes. These are the experiences that keep me going.

I know I'm losing her. It's happening right in front of me, but I'm holding on.

It's all about spending as much time together as we possibly can. To mark the anniversary of my dad dying, we watched the home videos he made in the early 1990s and ate his favourite foods.

My grandad, my mum's dad, appeared in them, and she was so elated to see him. She looked at me and said, 'That's my Dad!'

I can't put into words how magical this was.

Despite the challenges and frustrations, the days where it's hard to get Mum up, dressed and into the car, I wouldn't change anything.

**Gareth Davies, Birmingham** 

# in Castle Cary

I am a dementia advisor in Somerset and I support people in Castle Cary. The town recently had a competition to create scarecrows to display around the town. Over 120 were displayed and even brought interest from BBC Points West.

People at the local memory café took part and created Memory Mary. The café is run by a lovely team of volunteers led by health coach Steph Burr. Pictures were sent to me by another volunteer, Penny Steiner.

I refer people to the café and drop-in every couple of months to support this lovely group.

Julie Woan, Somerset







### **Telling Tales**

A carer in North Yorkshire has been sharing her experiences of her husband's young-onset dementia in a blog called Telling Tales.

Linda Barnes says, 'I was encouraged to start writing more than five years ago because a friend who suddenly found herself supporting an aunt diagnosed with dementia couldn't find any "instruction book".

'She knew my situation and that I dabbled with poetry and prose, and felt that I had a story that would not only inform but support and inspire others facing their own journeys.

'The relationship I have with my readers is a vital part of my life too - someone to share the daily truths, laugh and cry with me. Loneliness disappears when I write.

'But my overriding reason for writing is Ken, who in the early days was my biggest critic.

'We have gone from diagnosis to care home with just about every sort of emotion on the way - it's a real-life drama of tragedy and comedy.'

Read Linda's blog at

dementiadiaries.home.blog





### **Winning Christmas cards**

We're very pleased to share the winners of the Society's Christmas card design competition!

Jill Kellie, who created the delightful winning robin design, entered the competition in memory of her mother Doreen, who died in 2023.

She says, 'My mother loved everything to do with art and culture, and inspires me to paint.'

Jill says she was 'astonished' to win, adding, 'My mother loved her garden and would often talk about the robin that visited it.'

Susan Driver's runner-up star

design was also inspired by her late mum, Peggy Tyler.

She says, 'The idea behind my design is inspired by my mother who used to praise good effort or work by saying "gold star" or "you deserve a gold star for that".

'Mum developed Alzheimer's and passed away in 2018, so it seemed appropriate for my design to include a gold star.'

Buy Jill's design as a print or ecard and Sue's as an ecard from this autumn – see **shop.alzheimers.org.uk** or call **0333 366 0035**.

### The Dragon Story



A charming animation continues to help younger children understand dementia, especially when it affects their family.

The Dragon Story is a four-minute cartoon about a young dragon called

Simon, whose Grandpa Drake is losing and forgetting things.

Aimed at children aged five to nine, the animation was created by David Bute, son of Jennifer Bute – a retired GP who has young-onset Alzheimer's. It was written by her daughter Alison, who also did the voice over.

It can be used at home, or in schools, clubs and other settings. There's also a resource pack with discussion points and themes.

Watch The Dragon Story and download the free resource pack at gloriousopportunity.org/thedragonstory

# Hundreds of poems

Thank you to everyone who entered our 2025 poetry competition!

We've had over 300 entries from more than 200 poets, and our shortlisting panel is choosing from these so that our judges will be able to select winners.

We look forward to sharing the winning poems with you in the October/November issue, in time for National Poetry Day on 2 October.

If you missed the chance to enter our 2025 competition, you may be interested in the Poems section of the Members' Area of Dementia Support Forum – see **forum.alzheimers.org.uk** 

# Skiggle: share assistive products

When reader Jo McAvoy wrote to us asking how she could share products she'd got for her late mother, we weren't sure where to point her to.

Then we found the website of a disability charity called Skiggle. This helps people to share all kinds of assistive products, from mobility aids and chairs to cushions and pill cases.

Through its online community marketplace, people either give away or sell assistive products that they no longer need.

You can also raise an 'SOS emergency alert' with Skiggle if you have urgent need for a particular product.

You can find out more at skiggle.co.uk/dementia

### **Share**

Share your views, feedback and news – email **magazine@alzheimers.org.uk** or write to the address on page 2. We can consider contributions received by 5 September for the October/November issue (wording may be edited).

## **Coming up**

What's in store for you in Dementia together magazine, and how you can contribute.



Thank you to everyone who took part in the readership survey about our special June/July magazine.

We co-produced that issue with the Young Dementia Thematic Group, and we hope you can see how their ideas have already made a difference to our latest magazine.

Once we have the findings from the readership survey, we'll share these with you. We'll be learning from them to help decide how to develop what we do in future issues.

### **Never done before**

If you have dementia, is there something you only did for the first time after you were diagnosed?

Big or small, we'd love to share it with our readers. It doesn't have to be skydiving... though it could be! Perhaps it's learning something new or taking up a new hobby or activity?

Contact us to share what you've done that's new for you. Email us at **magazine@alzheimers.org.uk** or write to the address on page 2.

# Being prepared

For next issue, we'd like to hear your advice about how to prepare for a sudden change or new challenge when a family member or friend has dementia.

This could include having things in place for when someone needs more help around the home, or in case they need to move into a care home.

Or it may be something that would help if they became lost or went missing.

Is there anything you've done in advance so that you feel better prepared?

Or is there something that you wish you had done, which would have helped a difficult or stressful situation?

Please share your tips before 5 September. Please email us at **magazine@alzheimers.org.uk** or write to the address on page 2.

# Where's my puzzle?

If you're looking for the latest anagramword from Pete Middleton, don't despair – a new one will be back next issue!

In the meantime, see page 13 for information about signing up to receive puzzles in our monthly Brain Workout packs.

## **Competitions**



### Rosa mug and tray

We have a Rosa mug and tray set (see pages 28–29) for one lucky winner drawn from correct entries, and a two handled mug for two runners-up, all in their choices of design.

- Q: What designs are available for Rosa mugs and trays?
- A. Cat, dog or lilac.
- B. Mole, rat or toad.
- C. Pussy willow, dog rose or African violet.



### **Memory Walk goodies**

We have a dark blue or forgetme-not blue Memory Walk beanie hat for two winners drawn from correct entries, and dark blue or forget-me-not blue fabric wristbands for five runners-up.

- Q: When will this year's 12 Memory Walk events across England, Wales and Northern Ireland take place?
- A. From February to March 2025.
- B. During September and October 2025.
- C. In December 2026 and January 2027.



### **Hygiene sprays**

M Aldridge in South Yorkshire won a full set of BioBreeze sprays, while an anonymous reader and C Hall in Hampshire, M Volland and I Green in Cambridgeshire, J Casey in Greater London, N Godfrey and A Khan in Essex, S Tabrah in West Sussex, L Johnson in Berkshire and P Phillips in Mid-Glamorgan each won an Incontinence odour and stain remover spray. **Answer:** BioBreeze sprays use enzymes to eliminate odours and stains.

### Forget-me-not seedballs

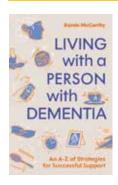
An anonymous reader and A Dean in Hampshire each won a Forgetme-not seedball tube, while J Dandy in Lancashire, R Bufton in Shropshire, B Mistry in West Yorkshire, Elaine in Lancashire and N Gent in County Durham each won a Forget-me-not seedball box. **Answer:** These forget-me-not seed balls contain chilli powder to deter slugs and snails from eating the young shoots.

### **Book giveaway**

S Thornton in West Yorkshire, Y Freeman in West Sussex, S Beynon in Warwickshire, T Archer in Kent and J Gaskell in South Yorkshire each won a copy of Has Anyone Seen Charlotte Salter?, by Nicci French.

### Anagramword

**Across:** thunderstorm, barbecues, holiday, blackberries, dandelion, tomatoes, recreation, suitcases. **Down:** salad bowl, roller coaster, wildflowers, sleeping in, wasp nest, sailing.



## **Book givewaway**

See p27 for a chance to win a copy of Living with a Person with Dementia, by Bernie McCarthy.

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

**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.



Choose from our many walks around the UK.

Memory

Join a community of thousands.

To remember the ones we love.

It will take a society to beat dementia.

Sign up to a walk near you at alzheimers.org.uk/memorywalk or search 'Memory Walk'.



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