June/July 2025

Dementia together

Alzheimer's Society

In this issue

Before and after diagnosis, the best and worst of care, postcode lottery

Special issue

Created with the Young Dementia Thematic Group

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Welcome

Hello everyone, a big warm welcome to this special issue, which has been co-produced with us, the Young Dementia Thematic Group.

I would like to introduce a very special bunch of people who strive relentlessly to put the dementia world right, in their own inimitable ways! Whilst we are all different individuals and characters we have many common aims, including a mission to change those misconceived perceptions of dementia.

We are: Martin Robertson, Martyn Colebourne, Mick Lambert, Tim Little and Martina Davis.

This co-production opportunity has been the most fantastic vehicle for us diagnosed as young onset to tell it as it is, warts and all.

We do it with humour, sensitivity and empathy, and as well as the funny we have not shied away from the difficult.

The drive within us has been the motivational inspiration for ensuring that this special issue in some way touches the hearts and souls of everyone, being at the same time empowering and giving hope. We want you to feel you are not alone in the challenges you face.

This issue has been co-production at the highest level and makes a great read, but there are no spoiler alerts here!

We couldn't go without expressing our grateful thanks to Hayleigh Kicks and Catherine Maguire, dementia advisers at the Society, who keep us in order!

Young Dementia Thematic Group: Martina, Tim, Mick, Martyn and Martin

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,
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Directions

Well, the time for goodbyes has come around quicker than I expected!

The five years since I started as chief exec have been very full ones. Full of challenges, but also of incredible achievement as we've pulled together to face them. And there's been more than enough joy along the way too – much of it from moments with amazing supporters, people with lived experience and colleagues that will stay with me forever.

I'm so proud of how Team Alzheimer's stepped up to support people through the pandemic's awful impact. Years later, we're still finding new and better ways to be there for people, in a world where the pace of change never seems to slow.

Thanks to relentless campaigns, more people than ever understand how dementia is one of the most important issues of our time. Crucially, more people than ever also know the Society is here to help.

I'm going to miss much about leading Alzheimer's Society, and there are many memories I'll be treasuring.

However, I know the organisation is only going onwards, upwards and doing even more to bring help and hope to people affected by dementia.

I've said this many times and it remains true – it's our supporters who make this possible. So, one last time from me: thank you!

Kate Lee
Chief Executive Officer

News

Reflecting lived experience

Society campaigners contributed to reviewing a key piece of government work in Northern Ireland this spring.

We want people affected by dementia to shape developments across the UK. As part of this, we brought campaigners Síle, Edward, Catherine and Ruth together for a 'co-design' day at Queen's University Belfast to share their different experiences.

First published in 2016, Northern Ireland's Dementia Learning and Training Framework aims to help health and social care staff to deliver the best quality of care.

Aisling Playford, our National Influencing Officer, says, 'We believe the involvement of our campaigners means the revised framework will better address the real-life needs of people affected by dementia.'

Síle, whose husband Stefan lives with dementia, said, 'After Stefan's diagnosis, it felt like a lonely road but after today, I don't feel that way anymore.'

Forget Me Not tea party

Join us this June and host a Forget Me Not tea party to raise funds for Alzheimer's Society. You can host a party on 21 or 22 June, or on any day in the month that suits you.

Whether it's a cosy catch-up at home or a workplace bake sale, every cuppa and tasty treat helps.

It's simple and fun – and a great opportunity to socialise with your favourite people, all while supporting the fight against dementia.

To register and download a free digital guide, visit alzheimers.org.uk/tea-party or call 0330 333 0804.

Photograph: iStock.com/Image Source

Cycle London to Brighton

Join us on 14 September for the iconic London to Brighton Cycle, a 55-mile journey from the heart of London, winding through stunning countryside to Brighton's famous seafront.

Cycling for a cause goes beyond the miles – every moment means more. Whether you're cycling in memory of a loved one or pushing yourself to help us power future life-changing research and support, we can't wait to welcome you to our team.

Visit alzheimers.org.uk/londontobrighton-sep or call 0300 222 5808.

Ready for the Ultimate Golf Challenge?

Get your mates together this summer and sign up for the Ultimate Golf Challenge. Take on 36 or 72 holes of golf in one day, at a green of your choice – it's all to play for!

From tee-off to the final hole, you'll be making a huge difference for everyone affected by dementia.

Sign up today to receive your free fundraising pack at alzheimers.org.uk/ultimategolf or call 0300 222 5808.

Local elections

In the run-up to local elections in England on 1 May, our campaigners took action to get dementia on the agenda everywhere.

Many of you asked local candidates about what they'll do to make dementia a priority, and to ensure their council has a dementia plan or strategy.

We want to see enhanced access to early diagnosis and high-quality dementia training for all health and social care professionals across England.

Together, we believe we showed candidates how important dementia is to their future constituents – thank you!

Balmoral Show

In May, we headed to Northern Ireland's largest agricultural event, the Balmoral Show in Lisburn, to raise awareness about dementia.

It's a major celebration of the region's agricultural industry, attracting around 110,000 visitors and featuring food, local produce, livestock, entertainment and over 500 trade stands.

Our staff and volunteers were there to promote local dementia services and opportunities to get involved in the Society.

It was a great opportunity for us to engage with thousands of people and make valuable connections with rural communities.

Wales conference

We'll be hosting the Wales Dementia Conference in July at the Pierhead Building in Cardiff Bay.

Sponsored by Luke Fletcher, Member of the Senedd and chair of the Senedd's Cross-Party Group on Dementia, it will bring together key decision makers, health and care professionals, people with lived experience, and researchers.

With a new Dementia Action Plan in the pipeline, now is the time to come together and put forward our priorities for the future of dementia policy in Wales.

Study on vaccine impact

Researchers are exploring whether shingles vaccines may reduce people's risk of developing dementia.

Pharmaceutical company GSK, which makes a shingles vaccine called Shingrix, is working with the UK Dementia Research Institute and charity Health Data Research UK.

They're analysing data from the UK's shingles vaccine programme.

This was expanded to include new age groups in 2023, so researchers now have access to information about more people.

Find out more about Society-funded research at alzheimers.org.uk/research

United Against Dementia Gala

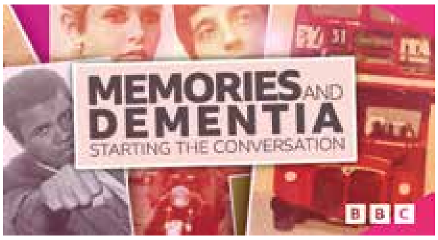
Over 200 guests from sport and business joined us for the United Against Dementia Gala at Lord's Cricket Ground in March.

Generously sponsored by our partner, the League Managers Association (LMA) and hosted by TV presenter Craig Doyle, the evening featured a heartfelt fireside chat with rugby stars Jamie George and Danny Care and cricketer Zak Crawley.

Thanks to LMA's support and a lively auction, we raised over £160,000 to help fund future dementia research leaders.

We're incredibly grateful for LMA's continued support for our Sport United Against Dementia campaign, helping us bring the sporting world together to fight dementia.

BBC dementia season



Did you catch any of the Memories and Dementia season across BBC channels in March?

Alzheimer's Society contributed to TV, radio and iPlayer programmes between 24 and 28 March, helping put the spotlight firmly on dementia.

People living with dementia and our experts appeared on flagship shows including BBC Breakfast, Morning Live and the Jeremy Vine show on Radio 2.

The BBC also used our expert insight and guidance to create special collections of shows on iPlayer and Sounds.

Catch up and find out more at bbc.co.uk/memoriesanddementia

Benefits changes

MPs will vote on the government's proposed welfare reforms in June.

The main benefits that could be affected are Personal independence payment (PIP), Universal credit and 'new style' Employment and support allowance.

If the legislation passes, changes to benefits aren't expected until April 2026, with others planned for much later.

Some changes will only affect future claimants, rather than people who are already receiving them.

If you are concerned about the reforms, call our Dementia Support Line on **0333 150 3456**.

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

Or find your local welfare rights adviser at **advicelocal.uk/find-an-adviser**

Your future care and treatment

Do you need advice on planning for future care and medical treatment?

Our updated factsheet on advance decisions and advance statements includes advice for people in England and Wales. It includes information on talking to professionals about future care, ReSPECT forms and a template for an advance decision.

For our Advance decisions and advance statements factsheet (463), see alzheimers.org.uk/publications or call 0300 303 5933.

Boosting research participation

Sahara, our dementia support service for South Asian communities in Greater Manchester, is helping to find how more people can be encouraged to take part in research.

Our charity partner Join Dementia Research is supporting Sahara to promote research opportunities and explore some of the barriers that stop people taking part.

Of the estimated 25,000 people in the UK who are from ethnic minority communities and living with dementia, people from South Asian backgrounds are the largest group. However, they are underrepresented in dementia research.

We're trying to understand why and how we can support more people to take part in research.

To find out more about research opportunities, visit alzheimers.org.uk/take-part-dementia-research

Launchpad for dementia ideas

We've unveiled the first 12 product ideas that we're supporting through the Society's Launchpad programme.

Launchpad is a four-month programme of events, talks and coaching. It helps entrepreneurs fine-tune their ideas with input from people living with dementia and professional experts.

We also support them with their business plans, so they can get their products manufactured and out to the people who need them.

Successful participants include antibacterial gummies to aid oral hygiene and virtual reality headsets to help reminiscence.

Interested in testing dementia product ideas? See **tinyurl.com/launchpadnoticeboard**

Your trek, your way

Organise your own fundraising trek and choose your own route, distance and dates. Trek on your own or gather friends and family for moral support – it's up to you!

Whether you walk coast-to-coast or tackle a local peak, your incredible efforts will support the fight to end dementia.

Sign up for free at **alzheimers.org.uk/your-trek** or call **0300 222 5808**.

Digital gift vouchers

Looking for gift idea from our shop for a friend or family member?

Buying them a digital gift voucher means they can decide which products would help them the most.

Available in £10, £25, £50 or £100 and valid for 12 months from the date you buy them, it couldn't be simpler to gift them. Vouchers are emailed to you with a code to be used at checkout. Visit **shop.alzheimers.org.uk** or call **0333 366 0035**.

Your poems

Our eighth poetry competition is open until the end of June, and you can enter up to three poems that you've written, each up to 30 lines long. For details, see page 39.

Celebrating our volunteers

It's Volunteers' Week from 2–8 June – the annual UK-wide campaign to celebrate and recognise the contribution of volunteers.

We're taking this opportunity to applaud our hundreds of amazing volunteers who give their all for people affected by dementia every day of the year.

From supporting Singing for the Brain sessions and providing telephone support to raising awareness and cheering our fundraising trekkers and runners, we couldn't do what we do without your energy and dedication.

Thank you!

Readership survey

Take part in our readership survey to tell us what you think of this special issue of Dementia together. If you didn't receive a survey with your magazine, email **magazine@alzheimers.org.uk** or write to the address on page 2. Alternatively, you can complete the online survey at **tinyurl.com/dementiatogether**

Society conference

Join our annual conference on 11 September online or in person at Convene in Bishopsgate, London.

Alzheimer's Society Annual Conference 2025 will focus on the healthcare inequalities faced by people affected by dementia.

Register today at **alzheimers.org.uk/conference** or call **0330 333 0804**.

Don't miss...

Which health and social care professionals can you turn to, and when? **See page 14.**

People with dementia share what's helped them to get through their very lowest times. **See page 16.**

Neil shares how years of discrimination and abuse for being gay affected his late partner's dementia. **See page 27.**

Jaymain saw some of the best and worst in dementia care with her late grandad and aunt. **See page 28.**

People let us know what they think of products designed to help with continence problems. **See page 34.**

Before and after

Martina Davis, in Cumbria, highlights two neglected aspects of life with dementia – what it felt like in the lead-up to diagnosis, and living independently afterwards.

'It was the best of times; it was the worst of times.'

It's funny really (well, in the context of a dementia diagnosis it isn't) but you never hear much about pre-diagnosis.

You're always asked, 'When were you diagnosed?'. That's fair enough, but little thought is hardly ever given to that horrendous time before a diagnosis.

I have posterior cortical atrophy or PCA. It's a type of dementia that affects the back of the brain which processes visual and spatial information. Other symptoms include light sensitivity, reading, spelling and problems with numeracy. All in all, it's a rare old mixed bag.

Subtle changes and impacts

Now, start to imagine what my life was like pre-diagnosis when nothing made sense anymore. The Dickens' quote I've used to open this article described my life perfectly.

I had been a business owner throughout my working life, the final one being a gallery I set up for local artists.

As a creative myself, it was to be the business that would see me through retirement. I'd be working in an environment I truly loved.

Have you ever noticed when things quietly change, you hardly pick up on them? For me when I look back, it was when I started to lose the ability to write with my left hand. I saw it as a nuisance so went on to teach myself to write with my right.

Quick read

I have posterior cortical atrophy (PCA), a type of dementia that affects the back of the brain which processes visual and spatial information.

In my pre-diagnosis life, dealing with increasingly frustrating symptoms and fears was often made worse by others' behaviours.

For me, receiving a diagnosis was a relief. I found my peace and could take up new opportunities – including to raise awareness.

Living independently and self-managing my condition can be hard work, but I draw strength from deep within to live my best life.

> **“There I was, trying to frustratingly understand why all this was happening. I was metaphorically shaking my fist skyward from time to time. What was wrong with me?”**

Up the down escalator

Things became more serious when I realised that lines on a page as I read would occasionally drop into the sentence below. I also lost my numerical skills.

From accounting to hanging the exhibitions, I managed everything in the gallery myself, but it was getting increasingly harder.

Then, for some inexplicable reason, I would miss my footing on a stepladder.

It was now becoming a regular occurrence for the people across the hallway of the beautiful Georgian building, to come running in shouting, ‘Have you fallen?’ Yep, there was me in a heap at the bottom of the steps again.

There I was, trying to frustratingly understand why all this was happening. I was metaphorically shaking my fist skyward from time to time. What was wrong with me?

I questioned myself, ‘Am I in the early stages of dementia?’ All the symptoms were stacking up.

Get a grip

As if it wasn’t bad enough to have my world spinning more than slightly off its axis, the impact of others’ behaviours was devastating.

I was asked, ‘What’s wrong with you?’, ‘For goodness sake, get a grip!’, ‘Are you losing the plot or what?’, ‘You never used to be like this!’, ‘You are driving me nuts’, ‘You are endless’ and so on.

I’ve always been a glass-half-full kind of girl, but I found it was becoming easier to deal with my fears rather than carry on explaining to those who thoughtlessly threw these remarks around. Yet, I could understand their frustration.

Strange really, but as I sit writing this, I realise that some people were more interested in persistently criticising and comparing me to the person I used to be.

They weren’t concerned with finding out what the matter was in the here and now, and asking how they could help.

The catalyst was losing my numerical skills – I went to see my doctor.

Peace at last

How on earth can you find peace when you have a dementia diagnosis?

For me, it was a relief to understand the reasons for everything that was happening. In turn, this turned into positivity despite me being young onset.

My glass was suddenly half full again. I became inspired to do as much as I could to raise awareness.

I got involved with organisations and whenever I got the opportunity, I tried to promote better awareness. I wanted to myth bust those incorrect preconceptions that surround dementia, such as believing that it’s an inevitable part of the ageing process. It ain’t. Far from it, in fact.

I also advocate wherever I can that more attention should be paid to pre-diagnosis. It’s such an important, scary and brutal period for everyone.

Part of finding my peace is helping others realise that you can have a life after your diagnosis, and a quality one too.

The trick is to recognise and accept where you are now.

So what if you can’t do what you used to? Life is still full of new opportunities. If there is anything that floats your boat, my advice is grab that tiger by the tail and go and do it pronto!

Art of self-management

I bang the drum for those who live alone and self-manage. It truly is an art. It’s also hard graft.

I’ve never thought about it like this before as I’ve always been seen as the queen of solutions (other folks’ words, not mine).

When I hit a challenge and work on finding that magical solution, there’s an enormous sense of achievement and so it inspires me to do more.

Some solutions, the successful ones, wah-hoo, I share. Others remain in the deepest darkness of the garden shed, where all the old pots are never to see the light of day again!

Seriously though, when you have to self-manage, you look at life in a completely different way and draw your strengths from deep within.

Empowering

It’s simple to manage strengths and weaknesses once you’ve acknowledged and accepted where you are in your life.

Recognise what you can no longer do and what you can do, eureka, that’s your starting point.

It’s critical to realise and motivational to understand that you are still in a position where you can do many things, enabling a good quality of life.

Don’t underestimate what an empowering time this is.

It’s true you may not have immediate help at hand, but help comes in all sorts of guises. Just do a stocktake and work out what’s important to you and target where that help comes from.

Challenging assumptions

Just as pre-diagnosis isn’t explored enough, there’s a lack of awareness about the number of people who are living alone and managing their dementia.

There is an automatic assumption that someone is caring for you. Many people have those who care for them right from diagnosis, but lots of us don't.

I have good friends who live alone and do it successfully.

Shockingly, one who was told on diagnosis that, because he lived alone, he would have to go into a care home.

Quite rightly he fought back. He lives a successful life with everything he needs.

Like me, he surrounds himself with gadgets, such as voice-activated smart speakers, which aid achievements, ensuring that we live a good quality of life.

Strength and courage

Sadly, there are misconceptions that self-management is easy to do. It isn't.

You need strength, courage, no end of patience and above all a sense of humour. You have to be organised and prepared to fine-tune things. We are under the same pressures as those who are caring or being cared for.

I've had experiences in group discussions about carers' hardships where I've felt the need to speak up for those of us who self-manage or live alone.

We are a group of people who are very much forgotten.

Life is not a rehearsal

I am pleased to say that many people respond well and say they've never thought about things from our perspective.

They now have the utmost respect and understanding for those of us who continually march forward, heads down trying to live our best life.

After all, it's the only one we've got!

For our Young-onset dementia: Understanding your diagnosis (688) booklet and Using technology to help with everyday life (437) 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.

Onset, diagnosis and now

How Sarah Creeth's vascular dementia has changed life for her and her husband Martyn.

Sarah

Who were you before onset?

Life was good. I was Principal of an educational charity for people with dyslexia, ADHD and dyscalculia. It was a busy job but I loved it.

I was an open, friendly person and liked to draw and paint. I sewed, knitted, crocheted and made patchwork quilts.

Martyn and I were looking forward to retirement. We wanted to buy a motor home to travel around the UK and had plans to do lots of things to the house.

Who were you before diagnosis?

In my early 50s I started getting overwhelmed, felt I couldn't organise things and was getting confused. I didn't feel in control and couldn't work out what I was supposed to be doing. I had to write everything down and that wasn't me.

I lost all my confidence and, in the end, I decided to leave my job. I was heartbroken. It was hard for me going to new places and meeting people, so I stopped going out and got quite depressed.

Who are you now?

I broke down when I got the diagnosis two years ago. I thought dementia happened to people in their 80s and this wasn't the way my life was supposed to be.

Martyn and I told our family straight away as we thought it was best people knew, but I still felt terrible.

Life can be a struggle but Martyn has been fantastic.

Our relationship has changed because now he is my 'carer' but what keeps us going is humour. We laugh all the time and try to find something good in every day.

> **"Our relationship has changed because now he is my 'carer' but what keeps us going is humour."**

Martyn

Who were you before onset?

I was deputy head of a prep school for 25 years. I worked long hours and it was stressful, but it was still a fabulous job. Part of my role was Head of Sport.

I left in 2016 but the school took me back as a senior master in charge of estates and preparing the school for inspections before I retired in 2021.

I was a hockey coach, I cycled and ran, and was looking forward to travelling and doing up our house.

Who were you before diagnosis?

After Sarah left work she became manic and withdrawn. She was seeing a therapist but I was concerned they were making her worse by dredging things up.

I knew Sarah wasn't right but I was at the peak of my career and we had a mortgage to pay. I couldn't give everything up to look after her, which made me feel guilty.

When she got the dementia diagnosis a few years ago it was a shock, but it was more difficult when we didn't know.

Who are you now?

Sport is an outlet and I have a strong faith which helps, as I feel God is looking after me.

I have learnt patience. I used to want everything now but now I am a lot more chilled.

Luckily I can leave Sarah at home and I make time for myself meeting friends for coffee, playing golf and helping out at church.

There are times when we have to cancel plans but you have to embrace it. This isn't how we thought things would be, but life can still be good.

New horizons

We meet people who've pursued fresh experiences and learned new skills after their dementia diagnosis.

> **Grab everything with both hands and make best of what you've got.**

Public speaking

After joining a peer support group, Joan Taylor in West Yorkshire has found her voice.

'I've always been a sociable person. I worked in a care home, organising activities and really enjoyed it.

'After my diagnosis, I felt horrible. I was in a big, black hole. I cried a lot. 'I didn't want to do anything or go anywhere. I just wanted to be at home because I felt safer there.

'When I joined the Voices Together group, I felt supported straight away.

'Everyone understood what I was experiencing because they were going through it too.

'Our focus is helping other people, showing there's life beyond your diagnosis.

'Through the group, I was asked to speak at an event about my experiences at a healthcare managers meeting in Leeds.

'Public speaking is a completely new experience, but I found it came naturally.

'I speak from the heart about dementia. I don't mind it if people ask me the difficult questions.

'I've since spoken at an event at the National Coal Mining Museum. Our group has also made an awareness video.

'I'd love to do more public speaking if the opportunity comes up.

'I'm in a completely different place to when I got my diagnosis. I don't want to hide away.

'I tell people, don't be afraid to give new things a try. Grab everything with both hands and make best of what you've got.'

> **Take all the time it needs and do a good job.**

Doing a master's

Veronica Ashby, in Derbyshire, studied for a master's degree in sustainability.

'My initial response to my diagnosis was denial. It shocked me so much that I refused to accept it was happening.

'As my memory worsened, I suffered with anxiety. Medication helped but I realised it was having a greater negative impact than my memory issues.

'To explore what was happening with my brain, I decided to complete some online short courses and became fascinated with sustainability.

'I wanted to learn more and test my mental capacity, so I enrolled to do a master's in the green economy at Bournemouth University.

'It was a 12-month, online course with online lectures and meetings as well as assignments. I developed strategies to enable me to manage the learning and the support of the staff was amazing.

'Studying has given me – and those who know me well – a new confidence and understanding that dementia need not govern your entire life.

'When people say, "I can't believe you have dementia," I think, "Well only part of me does!"

'Take it one small step at a time after your diagnosis. Tune into your own feelings and move on when you feel inspired. Take all the time it needs and do a good job.'

“Don’t let the things you can’t do stop you from doing the things you can do.”

Playing and composing

Steven Peacock, in North Yorkshire, has learned to play the piano and released an album of his own music.

‘Like many people, I often wished I could play an instrument.

‘I had never got around to doing anything about it until one day when I said to my wife Brigit, “I want to learn the piano”. This was a few weeks after I had been diagnosed with dementia.

‘I bought a digital piano and did some online tutorials. But this had its limitations, so Brigit searched for a teacher and found Annie.

‘It turns out that Annie was just the right person at the right time. We agreed we wouldn’t focus on grades and sitting exams but on the fundamentals, and we’d make learning fun.

‘I started composing my own music soon after beginning lessons and Annie suggested I make an album. I felt such a wonderful sense of achievement.

‘I play most days, even if it’s just a few minutes. It’s a powerful way to be in the moment. And, almost magically, it gives me a sense of me, who I am and who I’ve been. It’s a difficult thing to describe but I know what I mean.

‘It can be very difficult to imagine a positive future after a diagnosis.

‘But you can carry on doing the things you like and even go on an entirely new journey.

‘Brigit and I agreed early after diagnosis, “Don’t let the things you can’t do stop you from doing the things you can do.” It’s true. Do it. It works.’

“I fill my days with activities and learning, it’s helping my dementia journey.”

Educating in schools

John Hyde, in Somerset, visits local schools to talk with young people about dementia.

‘When I first heard about Alzheimer’s Society’s schools project, I thought, “I’d love to be involved in that,” and the rest is history.

‘It’s a symbiotic thing. I get a lot from it and the young people do too.

‘It makes them aware of their own inbuilt empathy.

‘If I could plant a seed in a young brain that might inspire future dementia research – imagine that!

‘They ask difficult questions. But I don’t mind, I’m there to educate them.

‘A few weeks ago, an eight-year-old asked, “Are you happy now that you’ve got dementia?” and the room fell silent.

‘I replied, “I’ve been a lonely person most of my working life. But because of my dementia I get to come here and meet you all, so I’m very happy today.”

‘I’m convinced that because I fill my days with activities and learning, it’s helping my dementia journey.

‘I’ve taught myself to play the ukulele, recorded podcasts, started to draw, written children’s books. I’m also a research volunteer and talk with medical students.

‘I used to work as a self-employed handyman. I was shy and introverted.

‘Dementia has allowed me the freedom to throw myself at things that perhaps I’d have been embarrassed to try before.

‘I’d always say to people keep doing and learning things.

‘I feel as though I’m about 10 times more alive now than before my diagnosis.’

For our Keeping active and involved (1506) booklet, see **alzheimers.org.uk/publications** or call **0300 303 5933**.

Who can help?

Which health and social care professionals can help you, and when?

When you're diagnosed

Different specialists at the memory service could help after your diagnosis:

Getting your medication right	**Consultant old age psychiatrists** or **specialist nurses** can prescribe and adjust any dementia medications.
Dealing with your diagnosis	**Clinical psychologists** may offer emotional support.
Building skills and knowledge	**Psychologists**, **occupational therapists** or **support workers** will run a cognitive stimulation therapy (CST) course.
Getting information	**Dementia support workers** or **dementia advisers** might work at the memory service, or at another local support service.

As things come up

Call the GP surgery for an appointment if you have a new health problem, or if an existing problem is getting worse. Other professionals can help with:

Problems communicating, eating, drinking or swallowing	**Speech and language therapist**.
Maintaining skills and independence	**Occupational therapist**, **adult social care team** or **telecare team**.
Problems moving around and staying active	**Physiotherapist**.
Foot care problems	**Podiatrist** or **chiropodist**.
Eyesight and vision problems	**Optician** or **optometrist**.
Hearing problems	**Audiologist**, often at a high street optician.
Difficulties with mood or behaviour	An **old age psychiatrist**, **specialist mental health nurse** or **clinical psychologist**. **Creative therapists** can also provide music or art therapy.
Relationship problems	**Counsellor** or **clinical psychologist**.
Nutrition problems	**Dietitian**.
Toilet and continence problems	**Continence adviser** or **community nurse**.

Ongoing help

Keep in touch with your local GP and community health services to help you stay as well as possible.

At the GP surgery, you'll normally see a **GP**, **physician associate** or **advanced nurse practitioner**. A standard appointment tends to be about 10 minutes, so tell them you may need more time when you book it.

Most GP surgeries have other professionals who support people with long-term conditions like dementia. These vary, but might include:

- **Care coordinators** liaise with different health services and can point you towards other support.
- **Clinical pharmacists** help you with medications – these should be reviewed at least once a year.
- **Mental health practitioners** help if you have severe or complicated mental health problems.

Others who can provide ongoing help include:

- **Community nurses** can visit regularly if you need nursing care at home.
- **Social workers**, usually from the local authority, may assess needs, arrange support and help with some costs.
- **Social care** or **homecare workers** help with tasks such as preparing meals, dressing and washing.

When you're not sure

A **dementia adviser** can help you work out what you need and where to get it – call our Dementia Support Line on **0333 150 3456** (see page 18).

Our My appointments (923) booklet can help you keep track of the professionals you see and what they say – see alzheimers.org.uk/myappointments or call **0300 303 5933**.

Opinion:
The postcode lottery must end

Martyn Colebourne in Leicestershire says that regional differences in care are further proof that dementia isn't prioritised.

In healthcare, 'postcode lottery' is a phrase people use to talk about the stark variations in access between areas around the UK.

I hadn't really thought about it until I started talking to people around the country who, like me, are living with dementia.

I had assumed that my experiences would be similar to theirs.

Extra challenges

I was diagnosed with young-onset dementia about a decade ago, in my 50s.

It led to some devasting changes in my life, including having to leave a job I loved.

I felt completely alone and had to proactively seek out support. It was a minefield, trying to work out what was available to me and how to access it. It added stress to an already terrible time.

Most people with a diagnosis are older and dementia services are usually designed to meet their needs. So, there are extra challenges if you have young-onset dementia, even though there are over 70,000 people living with the condition in the UK.

Different parts

I'm currently part of an Alzheimer's Society group called Young Dementia Thematic Group.

We meet regularly online and use our personal experiences, knowledge and skills to help the charity, including helping produce this issue of Dementia together magazine.

It's through this group that I get to interact with people living with young-onset dementia from different parts of the country, including Cumbria and Hertfordshire. Chatting to them about their experiences is really enlightening.

One chap in Essex has got a great set-up in terms of local dementia services. The care he receives on the medical side of things and everything else seems to be far superior to what we get here.

I think that if it can happen down south, then why can't it happen everywhere? Quality care and services should be consistent irrespective of where you live.

Wider debate

Without a shadow of a doubt, everyone living with dementia needs to have access to the same services, the same support.

But you've got to ask: why does this postcode lottery exist in the first place?

You could say that it shows a lack of awareness and urgency about dementia overall, even though it's the biggest killer in the UK.

We need to talk about regional differences in dementia care as part of a wider debate.

We need to pressure the government to make dementia a priority and act now on improving dementia services for everyone.

Become a campaigner

Dementia is the biggest health and social care issue of our time, and yet it's UK's forgotten crisis. Join us to make dementia the priority it needs to be – visit alzheimers.org.uk/campaign

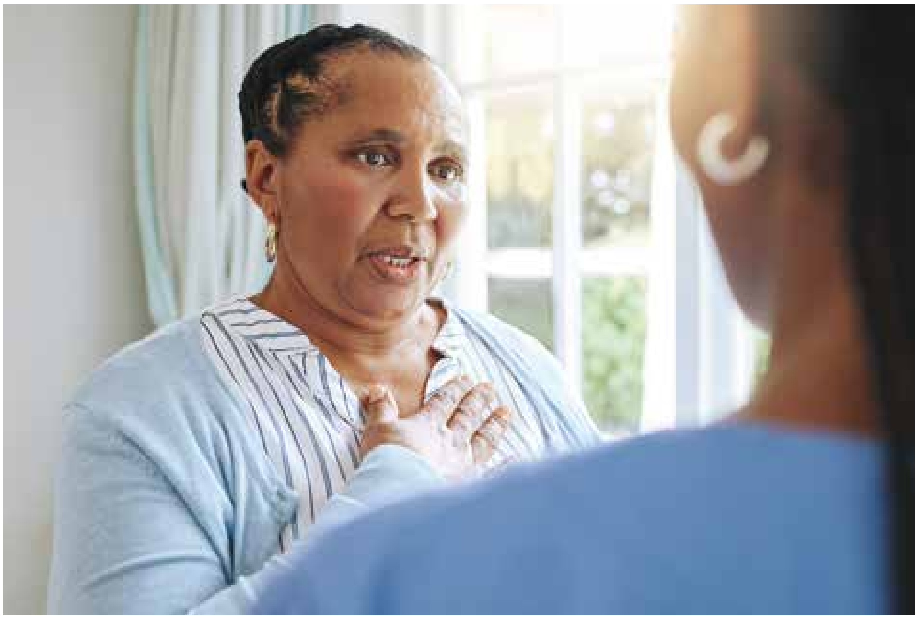
We won’t stop caring

Three people with dementia share some of their worst moments – and what’s helped them to find hope again.

Content warning: includes personal accounts of suicidal thoughts and suicide

We spoke to three people with dementia who told us about times they’ve questioned whether life is worth living, and even considered acting on these thoughts.

They share the things that have helped and continue to help when dealing with these feelings.


Photograph: iStock.com/PeopleImages

> **I get through with the support of my family and being honest about how I feel.**

Glimmers of hope

Anita Goundry in County Durham was diagnosed with Alzheimer’s disease and vascular dementia when she was 50.

‘I got my diagnosis over the phone and was left to cope on my own.

‘Covid hit and I couldn’t see a psychiatric nurse, nothing like that, and I spiralled. I was told I was depressed after a phone assessment, then I got a call to pick up some antidepressants. That’s all.

‘One day, I snapped. I debated whether my life was worth living. I was tearing my family apart.’

Anita started making preparations to take her own life, but thankfully she reached out.

‘We had an Alzheimer’s Society leaflet, it said “if you need help, ring us”. I called and if it wasn’t for the lady who answered, I’d have acted on those thoughts.

‘It’s not been easy since then. I will always be on antidepressants. I’ve been through more difficult times, especially since the death of my best friend.

‘I get through with the support of my family and being honest about how I feel.

‘When I recognise the signs, like not wanting to get up, I get help.

‘You’ve got to speak up and reach out as soon as suicidal thoughts come up.

‘Don’t think it’s a one-off because once they’ve been triggered, they tend to reoccur.

‘To fight them, you need help. You cannot do it all by yourself.

‘I managed to find a glimmer of hope. And I realised that while I couldn’t go back to the old me, I could be a new me and the best new me I could possibly be. Therapy helped me.

‘I started to go out and do things, I started to campaign about dementia. I’ve got new passions and hobbies. I found love again.

‘I liked the old me, but I quite like the new me too.’

> **If you are struggling, find someone to talk to – family, a friend or even a professional, they might be able to help you get out of the rut.**

Someone to talk to

An anonymous contributor was diagnosed with dementia at age 55 during the second Covid lockdown.

‘The news was delivered by phone on a Friday morning.

‘This catastrophic event left me floundering. I had no one to talk to,

Samaritans listen
Whatever you're going through,
you can call Samaritans any time.
Call **116 123** for free or visit **samaritans.org**

I spent the weekend on Google – in hindsight, not a good idea.

'There was only bad news. Sunday afternoon, I told my wife, "I want to go to Switzerland." Alzheimer's Society helped to change that mindset. That was not a comfortable place to be.

'My wife has been outstanding, not only in her support, but in recognising when I am getting low moods. Sometimes, I think I am just having a bad day, but it shouldn't be every day.

'I know I am not currently suicidal, as I have tried it in the past, twice. So, I can recognise the symptoms and hopefully get help before I reach crisis point.

'The first attempt was in 1999. That was a very low period in my life. Soon after this, I was diagnosed with persistent depressive disorder. People with this mild but long-lasting condition may also have bouts of major depression.

'When the symptoms were explained to me, I realised that I had been depressed for most of my life.

'I don't have a magical panacea. I just try to remember that every morning I wake up starts as a good day. It might go downhill almost immediately, but it has the chance not to.

'The main difference these days is I have someone to talk to. Also, a certain amount of self-awareness helps, not navel-gazing but being honest with myself and loved ones.

'I can't do it on my own, most can't, and those who claim they can are probably mistaken.

'If you are struggling, find someone to talk to – family, a friend or even a professional, they might be able to help you get out of the rut.'

> **"Most importantly, don't feel ashamed about how you're feeling."**

Little steps forward

Martin, in Aberdeenshire, was diagnosed with posterior cortical atrophy (PCA) in 2016.

'People with dementia sometimes think their families will be better off without them. The truth is they won't stop caring just because you're not there.

'PCA hits your emotions. One minute, you can be sky high and the next, you're down a rabbit hole. And certain things happened that made me go down that hole.

'I kept it to myself, I didn't tell anyone.

'Digging myself out was a slow process.

'My brother took his own life in the 90s. Thinking of him stopped me going any further.

'I have lifelong guilt about him. It never leaves. I couldn't do it to my family.

'I had counselling. I did things that made me feel wanted again. I'm now involved with research and various organisations, including a mental health charity.

'If you're sat at home, going downhill and able to use the internet, look for reputable organisations who can help or get to a library or health centre, they'll be able to give you information.

'Take little steps forward. Find distractions, focus on new things. Find something that engages your brain. If you can slowly shift your mind for a few minutes, it'll turn into a few hours, days, weeks.

'Get outdoors every day, even if it's five or 10 minutes. I go for a walk whatever the weather. Even if you're in a chair in your garden, that helps.

'Have a plan ready for times you know will be hard. Treat yourself.

'Feeling better isn't easy, and there's no shortcut. Remember, just because someone says something works for them, it might not work for you.

'Most importantly, don't feel ashamed about how you're feeling. You're not the first and you won't be the last.'

Support line: call us

Denise Maguire, from our Dementia Support Line, tells us how they're here to help anyone who needs dementia support.

Call our Dementia Support Line on 0333 150 3456 for personalised advice. Open Monday to Wednesday 9am–8pm, Thursday and Friday 9am–5pm, and Saturday and Sunday 10am–4pm.

To speak in Welsh, you can call 03300 947 400. Open Monday to Friday 9.15am–4pm.

To talk in other languages, call 0333 150 3456, say the English word for your language and end the call. An interpreter will then call you back.

If you have speech or hearing difficulties and use a textphone or adapted computer, use Relay UK to call our English-speaking Dementia Support Line on 18001 0333 150 3456.

I am a Team Leader on the Dementia Support Line. We are open seven days a week, and we stay open until 8pm on Monday to Wednesday evenings.

Our team is based in three locations – Birmingham, Warrington and Belfast. We provide a national service for people with a diagnosis of dementia, carers, family or anyone worried about their memory. We are often the first point of contact for people.

Sometimes people think that Alzheimer's Society only supports people who are affected by Alzheimer's disease. But we are here for everyone affected by any form of dementia, including young onset.

All sorts of calls

If you call, you will speak to one of our friendly and expert dementia advisers. They will take time to let you talk and tell your story. You can ask questions about anything, no matter where you are on your dementia journey.

> **“Sometimes just having a listening ear and sharing things can help put a situation into perspective.”**

We get all sorts of calls. They can be about practical situations, like how to get a diagnosis or how to plan for the future once you have a diagnosis.

There are also more emotional calls about the impact dementia is having on the carer or the person with dementia. Sometimes just having a listening ear and sharing things can help put a situation into perspective.

What you need

We offer advice and information, but we can also link you in with local dementia support services in your area, if that is what you need.

We can put you in touch with other useful services too, such as Lasting Power of Attorney assistance or our online Dementia Support Forum. We can also signpost to other organisations who may be more appropriate for your query.

We help to empower and instil confidence in our callers. It is lovely to hear, at the end of a call, the change in the caller's voice. That sense of relief and that they have a plan of action can be so powerful. It might avoid a crisis situation developing.

Positive impact

Educating family members in ways to communicate more compassionately with each other can have a hugely positive impact on how they navigate dementia together.

We often get feedback that the call made a difference, and it is rewarding to know that we have helped.

The message that we would like to get across is: don't be afraid to call. We are here to help.

Inspired ideas

Three inventive Alzheimer's Society fundraisers share their unique experiences and advice.

Photograph: Keery Irvine

There are so many ways to raise funds – how do you decide on an idea and make it a success?

Play to your strengths

Mark Bingham, in Belfast, held the first Rock for Alzheimer's gig in 2013. It's been going strong ever since, raising over £80,000.

Mark lost both parents to Alzheimer's. He was considering various ways to fundraise, but the winning idea came from him playing in a rock covers band. Their singer and drummer also played in an AC/DC tribute band.

'We asked the Empire Music Hall for a good price and off we went. I expected to sell 200 tickets, but we sold 500,' he says.

'Rock for Alzheimer's has taken on a life of its own. It's a rock gig, yes, but it's also a celebration.'

'Play to your strengths. If you have a passion and you have connections, leverage them.

'You need a lead-in with promotion, so my advice is don't rush.

'Contact your local Society fundraisers – they can help with branding, promotion and volunteers too.

'Be imaginative. Every year, we try make things different. We never take it for granted that it will sell out.'

Stand out

Angie Wild formed a crafters group in Tameside in 2023 and they've raised nearly £14,000 so far.

Group members are aged from below 40 to above 80, and some have direct experience of dementia. They've created everything from Easter chicks to forget-me-not cards.

'It's about more that the crafts,' says Angie. 'The group want to support people living with dementia. Joining also helps our members feel less isolated. There's always a cuppa waiting.'

'If you're looking to fundraise, our advice is see what people like, but give it an edge. Because we are a bit different to what anyone else does, our creations stand out.

'We try to keep things fresh – everyone comes to the group with different ideas.

'Promotion is key. The more we promote, the more people know what we do and support us. In fact, people now come to us.

'Reach out. Get people in your community to support you, whether it's raffle prizes or invites to events. Their generosity might surprise you!'

Get help

Derek Hernaman, in Devon, raised over £12,000 touring his vintage Land Rover and caravan – called George and Mildred – around the coast of Britain.

Derek wanted to fundraise for dementia and bowel cancer, which had both affected loved ones.

'Once I'd made a Facebook page and it was out there, I couldn't back down,' he says.

'My advice is, get help. I couldn't have done this without the people who donated to my fuel fund, and support from a mechanic friend. My son-in-law did the online, techie stuff. I have a very understanding wife too.

'People's generosity on the tour was also amazing. Many campsites waived their fee.

'Take time to speak with people. During my tour, people came to chat about their experiences, and it was a real eye-opener.

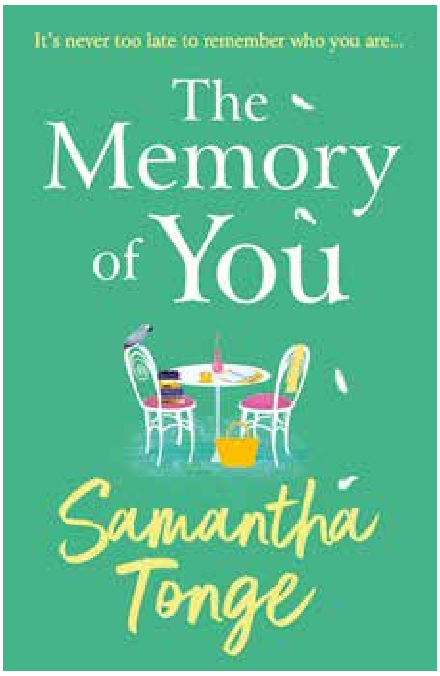
'Do something you enjoy and be brave. People told me that I was bonkers. When I broke down in the middle of Glasgow, I was beginning to think they were right.

'But it wasn't as daunting as you might expect.'

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

Book group:
The Memory of You

We read a novel from a best-selling author about a woman who unexpectedly finds herself working in the Wrong Order Café.



The Memory of You, by Samantha Tonge (Boldwood, 2023), 312 pages, £9.99, ISBN: 9781804154281. Also available as an ebook and audiobook.

Samantha Tonge is a best-selling author who's known for uplifting, emotional stories that are marketed as women's fiction. In her 2023 book The Memory of You, we meet Alex, a writer at a turning point in her life.

'An author whose career is going downhill finds herself working in a café to help a stranger,' says Jools in Suffolk.

'She's expecting a posh coffee shop, but discovers that the Wrong Order Café is exactly like its name – often customers will be given incorrect meals because some of the staff with dementia get their orders muddled up.'

Character growth

'My heart dropped when I saw the cover of this book,' says Alison. 'It's very much in the style of "chick lit" which, in my experience, can be full of sensationalist plot turns and very little real characterisation.

'Happily, my initial foreboding wasn't borne out by actuality. It's genuine women's literature, and I liked the fact that one of the principal male characters, Tom, used that genre to help him open up with his emotions.'

Anne in Wiltshire says, 'Thank you for introducing me to a book and author I may not have tried.'

'I felt slightly disbelieving of the plot line at the beginning,' says Jane from Kendal, 'but maybe life is about taking opportunities when they present themselves?

'It took me a while to get into this book, as the main character is not at all likable. But I would recommend readers to bear with it, the book and the characters (particularly Captain Beaky) will grow on you.'

Alisongs says, 'The first third of the book went into detail about a very unrelatable lead character – a driven, arrogant author – so much so I struggled to be interested.'

'I wasn't keen on the main character at first,' agrees Debbie P, 'but this shows how well the author put the character across. In fact, all the characters were good in their own right... oh, and the parrot was hilarious!'

Carole in Chepstow, whose husband has frontotemporal dementia, says this was the first positive book she's read about dementia.

'I got upset a few times when some of the negative aspects were discussed and about how I could relate,' she says.

'However, the story focuses on people living with dementia who are "still there" even though they are constantly changing.'

Page-turner

Alison says, 'There are the plot twists that I'd expected right to the end and, of course, the necessary love interest.

'There is also treatment of Alzheimer's, some of which almost, sort of, nearly comes close to reflecting the experience of unpaid carers.'

Debbie says, 'The book made me feel better in myself, as I recognised certain traits that my mum has shown in recent times. I always doubt myself as she's in a home now.'

'The book is nicely written,' says Jools, 'drawing attention to the fact that there are many forms and stages of dementia, and that many people still have sparks of their character inside them.'

‘I found the story had much more flow and relatability in the last third, which I read quickly and easily and enjoyed,’ says Alisongs.

‘The depictions of dementia were most authentic in the characters of Fletch and Norms, others could be quite shallow.’

Alison says, ‘All in all, I found this a page-turner and I did find myself becoming invested in the character of Alex.’

> **“The book made me feel better in myself, as I recognised certain traits that my mum has shown in recent times.”**

Love and acceptance

For some reviewers, the book speaks more to readers about menopause than about dementia.

‘It’s very much a book about picking yourself up after a breakup and a midlife gap year for the menopausal,’ says Alisongs.

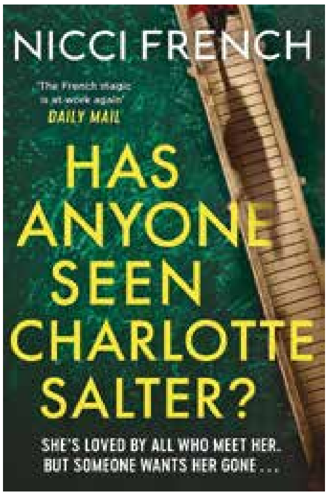
‘Dementia is usually characterised as loss of memory – and that’s the same here,’ says Alison. ‘There’s lots more involved, and carers may well be a bit fed up with people thinking that it is just about memory!’

However, Carole says she’s already recommended it to friends to help with their understanding of dementia.

Debbie agrees, ‘I would recommend the book firstly to anyone whose relative or friend has or is showing symptoms of dementia, but also to help anyone understand how dementia affects not just the person who has been diagnosed but the people around them.’

Jane says, ‘This book made me think deeply about what is important in life, that less is more, about friendship, love and acceptance, and that life doesn’t end upon receiving a diagnosis of dementia.’

‘The thing I will take out of this book,’ says Carole, ‘is that being perfect is really not that important. It doesn’t make you happy and to get to perfection is a very lonely path.’



Your turn

For our next book group, we invite you to read 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.

Tell us what you think of this thriller about a family with a long-disappeared mother and a father whose dementia is getting worse.

Email **magazine@alzheimers.org.uk** or write to the address on page 2 by the end of 3 July so we can share your comments in a future magazine.

Book giveaway

We have five copies of Has Anyone Seen Charlotte Salter? to give away – email **magazine@alzheimers.org.uk** or write to the address on page 2 by the end of 15 June quoting ‘Seen’ to enter (see page 38 for terms and conditions).

Travel for all

The 75-mile Bentham Line is leading the way for dementia-friendly rail travel. Antonia Kanczula jumped on board to find out more.

Quick read

The Bentham Line runs a dementia-friendly rail service from Leeds to Morecambe Bay.

The fully functioning rail link passes through incredible Yorkshire and Lancashire scenery.

By training staff and adapting facilities, the journey is more inclusive for people affected by dementia.

Dementia-friendly activities have also been developed along the route.

Rail travel can be a lifeline for people affected by dementia, but it brings a range of challenges too.

On the Bentham Line - a fully functioning rail link rather than a quaint heritage ride – every difficulty has been considered. In 2019, it was recognised as the UK's first dementia-friendly railway line.

The line is named after a small Yorkshire town on the route and operated by Northern. It runs from the hubbub of Leeds to the Lancashire seaside resort of Morecambe, past miles (and miles) of incredible scenery.

'It shows what can be done if you bring all the right ingredients together and have an open dialogue with the community to find out what their needs are,' says Catherine Huddleston, Community Rail Partnership (CRP) Officer for the line.

Early stages

The Bentham Line CRP was set up around 20 years ago to improve services and develop community links.

It's one of over 70 CRPs around Britain.

The line's dementia-friendly initiative formally launched in 2018. However, the first seeds were sown years before with a sample trip for people living in a care home, explains Rod Tickner, Vice Chair of the CRP.

'Our aim was to make the Bentham Line a centre of excellence in terms of understanding how community rail can help those with dementia to still lead an active life and feel part of society.'

Passion project

With involvement from national, regional and local community organisations, including Alzheimer's Society, the CRP's approach has many aspects.

'We've gathered together all the pieces of a jigsaw puzzle to create an accessible journey, one that takes into consideration all the difficulties that a person with dementia and those caring for them might experience,' says Catherine.

Key to the project is raising awareness among staff and volunteers about dementia.

'They're all offered training and the opportunity to become a Dementia Friend,' explains Rod. He has personal experience of dementia, after caring for his wife, and is a Dementia Friends Ambassador.

Paul Mason, train conductor on the line, says he embraced the opportunity after experiencing dementia in his own family.

'There's not enough public awareness of how to support people with dementia and I'm really proud that we're doing our bit to make a difference.'

> **Dementia-friendly journeys are now available on the Esk Valley line in North Yorkshire and the Settle–Carlisle line.**

Accessibility

There's been a concerted effort to make stations along the line more accessible.

There are limitations given the structures and facilities are largely Victorian – the line was first opened in the mid-19th century. But the aim is always to support passengers and their carers so they're able to travel with confidence.

'We worked with Alzheimer's Society looking at every aspect of the stations, including the signage, the lighting and the atmosphere,' says Catherine.

Stations along the line are 'adopted' by local groups, who have improved platforms using everything from artwork to retro travel posters.

'What helps people affected by dementia also helps other passengers who may have physical and hidden disabilities,' adds Gerald Townson, the CRP's Chair.

Rail to trail

Another unique aspect of the Bentham Line is a range of dementia-friendly activities offered along the route.

These were created in collaboration with people affected by dementia. Easy-to-follow walking routes have been developed at Morecambe, Bentham, the Forest of Bowland – an area of outstanding natural beauty – and Saltaire, a UNESCO World Heritage Site.

There are reminiscence activities too, available through local dementia groups. These include an immersive trip to Carnforth, where scenes from the 40s classic film Brief Encounter were filmed.

'We see the line as a gateway to opportunities. There are so many amazing things along and near it that people affected by dementia might not otherwise feel able to access,' says Catherine.

Inspire and influence

The influence of the Bentham Line is beginning to ripple out to other rail lines.

'Dementia-friendly journeys are now available on the Esk Valley line in North Yorkshire and the Settle–Carlisle line – they're taking the idea we started,' explains Gerald.

'Our work has also been picked up by the Department for Transport as it works to set up Great British Railways, the new public body that will operate the national rail network.'

Rewarding work

Accolades and achievements aside, the Bentham Line team says it's the very personal impact of their work that gives them the most satisfaction.

Experiences such as seeing carers bond with one another, or watching people's excitement as they glimpse the shimmering waters of Morecambe Bay or the soaring Yorkshire peaks of Pen-y-ghent, Ingleborough and Whernside.

'The greatest reward is to see the expression on people's faces and to interact with them. Above all else, they're appreciative of the care and attention they receive,' adds Gerald.

'We have an extra glow of pride thinking about how the project benefits people in so many deeper ways – including our staff, who take what they've learned into their own lives and families.'

Passenger Assist for you

Do you need help when you're travelling by train?

People with dementia can request free help in advance using Passenger Assist. So can people with other disabilities, impairments and needs.

Passenger Assist could help you to get around stations, get on and off trains, and in other ways too.

Even if you're travelling on services run by different train companies, Passenger Assist can cover the whole journey.

To request help in advance, use the **Passenger Assist** app from Transreport, visit passengerassistance.com or call **0800 022 3720** and select option 1.

Bringing back smiles

Care home residents who have dementia often struggle to see a dentist. Heather Stephen learns how a ground-breaking project in Essex is changing that.

Quick read

An NHS project in mid and south Essex is making it easier for people with dementia in care homes to get dental treatment.

Dentists visit care homes to give check-ups and treatment, and train care staff in oral hygiene.

Dentist Stephen Denny underlines how important oral health is for a person's overall health and wellbeing.

Care home manager Torie Sabbarton says the project has had a phenomenal impact on residents.

John Murphy, who has dementia, is one of over 5,000 care home residents to benefit from a dental initiative from NHS Mid and South Essex Integrated Care Board.

The drive to improve access to NHS dental care for this vulnerable group has meant John's had check-ups, a filling and a deep clean so far.

'The scheme has been amazing,' says Leanne Lea, Home Manager at Silverpoint Care Home in Canvey.

'People with dementia can get stressed leaving a familiar environment but under this scheme, problems can be picked up while they are in the comfort of their own home.'

Access to care

The project launched in 2023, linking 285 homes with 11 dental practices to treat residents who often find it challenging to get to a dentist.

For Stephen Denny, a dentist who helped set up the project, this work is close to his heart. His mother had vascular dementia, so he knows how the condition can limit access to care.

'For most care home residents, visiting a dental practice isn't just difficult, it can be impossible,' he says.

'Physical issues can make travelling to a dental practice or transferring into a dental chair unthinkable.

'Dementia can make the unfamiliar and clinical environment of a dental practice overwhelming. And non-verbal residents can't even express their need for treatment, leaving them in pain for many years.'

Many people living in care homes don't get regular dental checks because of limited mobility and long waiting lists for community dentistry.

But Stephen says this project has allowed dentists to identify problems that could affect eating and drinking. These problems can also point to serious issues such as blood clots, heart problems, diabetes, oral cancer, pneumonia and bronchitis.

The work has been such a success that it's been commissioned across mid and south Essex for the next five years. It's hoped it will be picked up in other areas of the country too.

Learning experience

Under the scheme, dentists carry out regular checks at care homes and respond to treatment requests from staff. They also train home staff in dental hygiene and how to identify problems.

The project has been a learning experience for many dentists in treating older patients with communication challenges.

Dentist Tony Clough says, 'We've learnt to communicate as clearly as possible, take our time and never force something on them that they are not comfortable with.'

Stephen adds, 'The idea of delivering services outside of our clinics was quite daunting, and for the first few visits we took far more equipment than we needed. But we have refined our system to include most of what we need.'

Tony says, 'We can see we have made a difference in terms of residents' oral health, but also the confidence of carers to manage oral health.'

Phenomenal impact

Silverpoint Care Home has benefited from the project for the last year. Torie Sabbarton, Operations Manager,

> **The gratitude we’ve received from residents and their families has been overwhelming.**

says the impact on residents has been phenomenal.

‘If you have dementia, it is really difficult to get to a dental surgery and travelling to an unfamiliar place can be quite traumatic.

‘Many residents may not have seen a dentist for years as they don’t normally come out to care homes, so we’re grateful for the project.

‘The staff training has been second to none and they now know how to do oral health checks to gather information they can share with the dentists.’

Torie calls the project ‘trailblazing’. ‘Poor dental health can have a massive knock-on effect on physical health,’ she says, ‘but if you can help residents be able to eat and drink properly again it can bring so many benefits to their lives.’

Stephen adds, ‘The gratitude we’ve received from residents and their families has been overwhelming.

‘For many residents, this is the first time in years they’ve been pain-free or able to eat comfortably.

‘It’s rewarding to see them happy and more confident socialising again.’

For our Dental and mouth care (448) factsheet, see **alzheimers.org.uk/publications** or call **0300 303 5933**.

A friendly voice

Eden Byrne, in Belfast, shares why she loves being a Companion Calls volunteer.

My Granny, who passed away last September, had dementia and I used to look after her when my Grandad went out.

I was glad to be there for her, but it could be emotionally challenging as she could get quite distressed at times.

From this experience, I wrote a blog about being a young carer for Alzheimer's Society. I was looking for a volunteering opportunity in a cause I was interested in when I found out about Companion Calls.

Anything and everything

I have been volunteering with Companion Calls weekly for almost a year now. The calls last about 40 minutes, and I have been with my current lady for about six months.

Most volunteers call a couple of people a week, but I chose to take on one person. People can be referred by a dementia adviser or they can refer themselves.

We talk about anything and everything. My lady, who has dementia, has a lot of health challenges, so she vents about that. And we talk about gardening, which she loves and the funny things her cats get up to.

Training and support

I had quite a lot of training for the role, from safeguarding to conversation topics and listening skills. It was very interesting and gave me an insight into how dementia affects people.

I enjoy supporting people and it is nice to meet other volunteers through our monthly Zoom meetings, where we share anything which has come up and listen to guest speakers.

When I'm not volunteering for Companion Calls, I look after my 18-year-old autistic brother, I work as a youth adviser for a charity which supports young people with autism, I am a volunteer befriender for Deaf Blind UK and Age UK NI, and I am studying information and communications technology at college – so I am quite busy!

More confident

I think the calls reduce isolation and loneliness, and give people the chance to talk about whatever they need to. Most people have their family, but they don't always want to bother them and they know we are here for them every week.

The calls give people company and the chance to open up. Sometimes this can be quite challenging for volunteers, but it is important that they get the chance to do that, and we support them the best we can.

Volunteering with Companion Calls has given me a great opportunity to connect with different types of people and manage different situations, and I am a lot more confident now as a result.

Be yourself

It can be quite daunting making that first call if you've never done anything like this before, but my advice would be – just be yourself and keep an open mind, as everybody you talk to is different.

People with dementia can take longer to process things, so give them time, let them lead the conversation, and don't be tempted to jump in too soon.

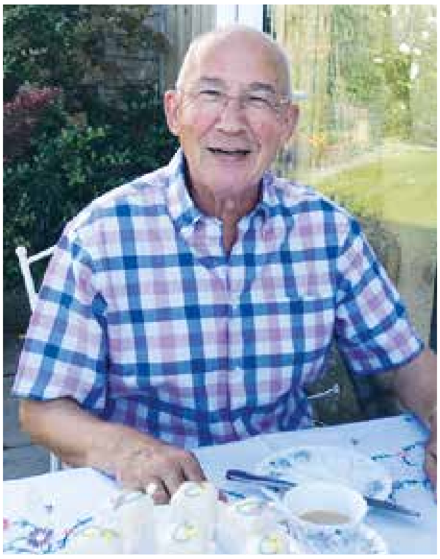
I look forward to my weekly calls so much. My lady is a good friend, and I get as much from the calls as she does.

Volunteering has helped me develop patience and listening skills, it is a great way to give back to my local community, and most of all, it is great fun!

Companion Calls are regular, friendly phone calls to people with dementia and carers. Find out more and sign up as a volunteer at **alzheimers.org.uk/companion-calls** or call **0300 222 5706.**

Finding meaning

After caring for his late partner, Neil Cutler is determined to improve support for other LGBTQ+ people affected by dementia.



It is 20 years since Neil Cutler asked his late partner, John, to see their GP about his memory problems. Dementia was the last thing on his mind.

'In those days, we put it down to old age. I thought well, he's nine years older than me – it's probably just one of those things.'

Neil had taken early retirement when they moved to North Yorkshire in 2002, and John's symptoms were too gradual to notice at first.

'Once you start to live with somebody 24/7,' says Neil, 'you don't notice the changes so much as if you were out to work all day.'

Very adept

Years of discrimination and abuse for being gay meant John had also learned how to hide things.

'He was very adept at covering up our relationship. As dementia started to set in, he was still using those techniques.

'We really struggled. He got very aggressive at times. He could be really nasty, very verbally abusive.'

'We just kept going, but then it got to a stage where his memory was really bad.'

As John's dementia progressed, things only got worse.

'The last 10 years of his life were awful, and the last three were extremely awful.'

A long shadow

It's usual for people's earlier lives to colour how dementia affects them. John's experiences of homophobia cast a long shadow.

He was already in his 30s in 1967, when being gay began to be decriminalised in parts of the UK.

'He'd spent the vast proportion of his younger years realising and coming to terms with his homosexuality,' says Neil.

'It clouds people's judgement when dementia sets in, because it puts them back to those scary times.

'We didn't get together until 1974. Being openly gay was really frowned upon. You suffered abuse, sometimes gay bashing. When we were out and about, he'd say, "We share a house, but we're cousins."'

Despite continued stigmatisation of gay people through the 80s, Neil says he and John shared some wonderful times together.

Still tainted

But decades later, their experiences of dementia care were still tainted by homophobia.

'I didn't realise until recently, being gay was still classed as a mental illness by the World Health Organization up until 1990.'

Plenty still needs to be done to address prejudice against gay and other LGBTQ+ people in the UK. For all the progress made here, the situation is much worse in many other places.

This affects the experiences and attitudes of people from around the world, including health and social care professionals.

Neil recalls a particular mental health unit nurse who treated John very badly.

'You'd like to speak up, but you just think, how's he going to be treated when I'm not here?'

After John moved into a care home, Neil remembers another resident's wife who never spoke to him again after learning they were a couple.

Improving support

Thankfully, Neil did find some invaluable help – especially from Dementia Forward, a charity covering York and North Yorkshire.

This left Neil determined to improve support for other people affected by dementia too.

After John died in 2015, Neil became a trustee of Dementia Forward and joined York LGBT Forum. He delivers LGBT awareness training to care staff and shares his experiences with healthcare students.

It all helps him to find meaning in everything he's been through.

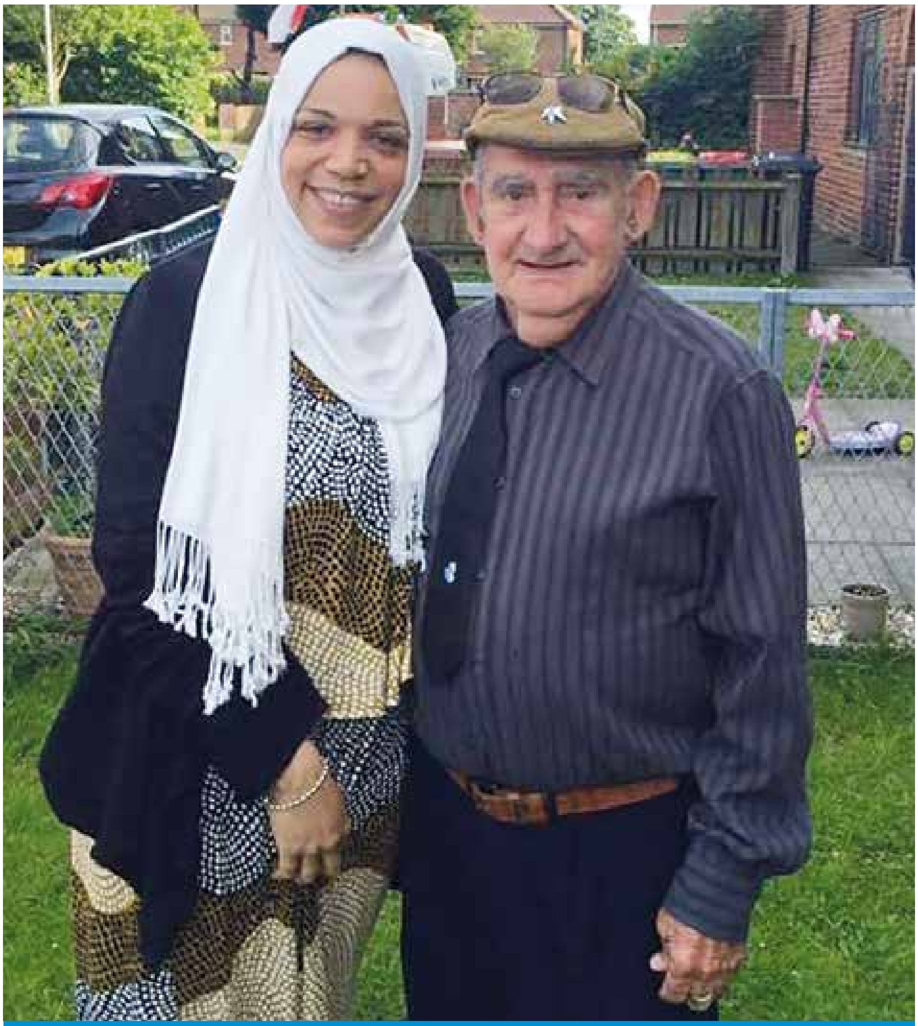
'Hindsight's a wonderful thing, isn't it?' says Neil.

'You can look back and think, "Yes well, this most probably all fell into place for some very good reason."'

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

The best and worst

Over the years, Jaymain Parkes has seen some of the best and worst in dementia care. Margaret Rooke speaks to a woman who wants dignity for everyone with dementia.



Quick read

Jaymain Parkes, in Bradford, has had two very different experiences of dementia in her family.

With her late grandad's vascular dementia, Jaymain quickly learned to take a confident role in his care.

But there was a lack of specialist support for her aunt, who had a learning disability as well as Alzheimer's.

Jaymain wants a care system that offers understanding and dignity for everyone with dementia.

When Bob Broadbent saw a neighbour in Bradford struggling with dementia, it prompted a fear of losing control and being ridiculed.

Bob begged his granddaughter, Jaymain, 'Please never let me get like that.'

When he became forgetful, his fear increased. 'I'm losing it,' he confided. Luckily, he and Jaymain couldn't have been closer.

Jaymain Parkes, now 50, a school counsellor and therapist, says, 'My grandad looked after my grandma until she died. He brought me up and looked after my children.

'He did backbreaking work as a binman and coalman to support the family. He meant everything to me.'

Misplacing things

Jaymain had also begun to feel concerned. Bob was misplacing things, missing doctor's appointments and forgetting to take tablets.

'My grandad was the one who kept the world running, so this behaviour was significant,' she says.

Bob's GP referred him to the memory clinic. Even before the appointment, Jaymain started to notice letters and numbers missing when Bob wrote something down.

At a follow-up appointment, the doctor asked Bob if he wanted to know everything or for the news to be softened.

'Grandad said he wanted to know everything. The doctor said he had a "really yucky disease called dementia", specifically vascular dementia.'

An active role

Jaymain realised early on that she'd have to take an active role in Bob's care and treatment.

After they'd agreed not to try one medication due to its side effects, Jaymain found it had been prescribed anyway. She got it removed.

Thankfully, they had met someone from Alzheimer's Society at the memory clinic.

'She gave us a booklet that contained information you might need at different stages, from making a living will to end-of-life decisions – things that hadn't been on my radar.'

Then Jane Williams, a Society support worker, contacted them.

'She helped me see I was an expert in Grandad's life, and he was an expert on his own experience. We knew best when it came to his rights, wants and needs. This gave me confidence.

'I thought, "We're living with this. What can we do to make life as good as possible?"

'I bought a whiteboard and wrote all his activities on there, from Monday to Friday. This helped until the end of his life. I also bought a clock that said whether the time was morning or evening.

'Jane told me that when someone repeatedly asks the same questions, that can be a sign of anxiety. I figured out with Grandad what his anxieties were.'

Dealing with professionals

Having confidence with healthcare professionals proved useful.

'At one point, Grandad had a severe gut infection. He lost weight rapidly, wasn't eating and was hallucinating.

'In hospital they asked if he was "end of life". I told them, "He was independent last week."

'They thought I was deranged! I was panicking, desperate for someone to listen to me.

'Then I said to a consultant, "Please look at this video. This is my grandad in London, pushing around his great-great grandchild last week. This is not an end-of-life situation."'

Mercifully the consultant took notice and prescribed treatment. After this, Jaymain filmed and photographed Bob regularly to prove how well he was.

Sadly, Bob didn't survive the Covid pandemic. Although dementia was given as the reason for his death, Jaymain believes he died of an untreated infection because the right care wasn't on hand.

'Covid was horrific, and now it's just back to business as usual,' she says. 'We fought so hard until then, and he had an amazing life.

'We got him his first passport at 78, and we had holidays all over. We went to Andalucia, staying in a villa on the mountain. We saw history in Istanbul. He went on a camel ride in Lanzarote.

'In London we went to see the sights – he loved Madame Tussauds. He went to Blackpool, Scotland and Wales. We did everything.'

Another family member

It wasn't long before Jaymain began to worry that dementia may be affecting another family member.

Jaymain's Auntie Irene had been born three months premature in 1958, weighing just 2lbs. Astonishingly she survived, but with a learning disability. For many years, Irene lived her life independently. She was known in her community and her local shop.

But Irene found it difficult when there were changes in services or the community. Life also became harder when she was forced to move because of the 'bedroom tax'.

Then an infected horsefly bite led to sepsis and a flesh-eating condition, necrotising fasciitis. This needed many surgeries and Irene started deteriorating fast.

Irene was vulnerable to people taking advantage of her. She became besotted with a man who stole from her and neglected her.

The family was terrified Irene would die in terrible circumstances.

She missed memory clinic appointments and was neglected at home. They sent the man packing, and Irene blamed Jaymain.

Irene finally received a diagnosis of Alzheimer's and was placed on medication.

'Within two weeks of starting that medication,' says Jaymain, 'she went from sad to aggressive. She was paranoid about me and the nurses.

'Everyone struggled with her. Eventually she had to move into a care home and then a mental health hospital.

'I watched her decline. I begged for her to be treated with care and seen as someone frightened, not angry.

'But because she had a learning disability, I didn't feel informed enough to challenge what was happening. And because Irene didn't trust me, she wouldn't give me power of attorney.

Everything a battle

Although Jaymain got information from Alzheimer's Society, there was a waiting list for more specialist support.

'I had to fight to stop doctors ignoring me. Everything was a battle. The treatment of my auntie was appalling.

'Irene didn't come under older people's services. She didn't come under learning disability services. We need to get the health system and social care right.

'I could look after my grandad because we always put his best self forward. My auntie didn't have anyone to do that for her.

'The dementia unit where she died was wonderful, but all the health service saw was crisis after crisis. Services were not dealing with each other.

'I know that if Alzheimer's Society was looking at my auntie, they would see her as a whole – as a young woman who liked dancing and singing, whose experience was valuable. People would have learnt from her.

'I know what the system can look like when it works well, when the people looking after you understand your needs.

'This is what we need for everyone.'

For our Learning disabilities and dementia (430) factsheet, see alzheimers.org.uk/publications or call **0300 303 5933**.

For 10 one-page summaries of our most popular information on dementia, including links to audio versions and more, visit alzheimers.org.uk/helpsheets or call **0300 303 5933**.

Explaining changes to youngsters

‘We told my eight- and 12-year-old kids about Mum’s dementia when she was diagnosed. Now her symptoms are more noticeable, what can I say to help them deal with this?’

It’s helpful that you spoke to your children about your mum’s dementia diagnosis.

As her condition progresses, they’ll probably notice more changes. These could be in how she behaves and what she’s able to do with them.

Changes in behaviour

Perhaps there’s something new that your mum has begun to do. This could include becoming confused about who people are or where she is.

She might feel anxious or frustrated when this happens. That could also affect her behaviour. For example, she might ask repeated questions or become agitated.

These changes can be particularly confusing and upsetting for children and young people.

Talk to your kids about how dementia is causing these changes in your mum’s behaviour.

Children might think they’ve done something wrong to cause the changes. Make sure they know they’re not at fault.

Encourage them to share their thoughts, feelings and questions with you.

They might feel embarrassed about some of the things she does. Or they might feel bored or annoyed by repeated questions. Reassure them that it’s OK to feel sad, confused or frustrated.

Changing relationships

Your mum may not be able to do the same things that she used to do with your kids.

They could feel a mix of loss, anxiety and other emotions as they adjust to this. They might also worry about future changes.

Reassure them that your mum still loves them and focus on what she can do with them. Emphasise the importance of spending time with her so they can show her they care.

By doing things with your mum and talking with her, they are helping the whole family to support her.

Answer their questions honestly, using language they’ll understand.

Don’t be afraid to use humour if it feels appropriate. Laughing together can help sometimes.

Things to say

There’s no one ‘right thing’ to say. Different children and young people will be reassured and helped by different things. However, here are some ideas:

- **Explain the changes: ‘Grandma’s illness is making it harder for her to do some things. She might seem different or confused.’**
- **Be honest but gentle: ‘It’s normal to feel sad or upset about the changes in Grandma.’**
- **Reassure them: ‘Even if Grandma doesn’t always remember us, or if she says unkind things sometimes, she still loves us very much.’**
- **Encourage questions: ‘If you have any questions or feel worried, you can always talk to me.’**
- **Highlight the positive: ‘We can still enjoy today and make happy memories with Grandma.’**
- **Provide support: ‘It’s OK to feel sad, angry or confused. I’m here to help you through it.’**

Advice and tools

For our Supporting children and young people when a person has dementia (515) factsheet, visit **alzheimers.org.uk/publications** or call **0300 303 5933**. This includes other useful organisations and resources.

There are many books with stories and information about dementia for a range of age groups. Some are included in the carers and family section of Reading Well for dementia’s book list – see **readingagency.org.uk/reading-well** or ask your local library.

Stories on repeat

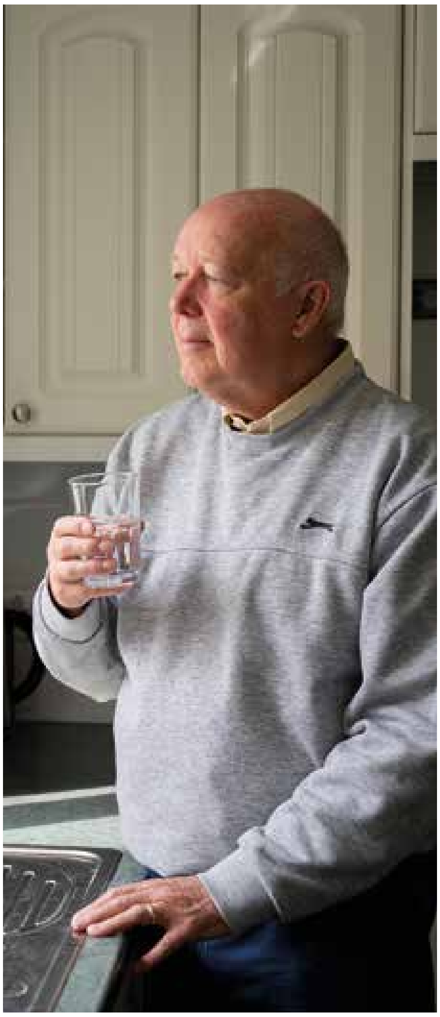
Advice about how to respond if a person with dementia tells you the same things over and over again.

It can be hard to know what to do if a person with dementia tells you the same things repeatedly.

On our Dementia Support Forum, people with experience of caring for family members recently helped a homecare worker who asked about this.

One person they were supporting told them the same three stories over and over, and they were finding it difficult to respond.

Thankfully, forum members were on hand with their advice:



‘I found going through old photographs helped trigger some new stories, which helped divert my person with dementia from always repeating the same story. She defaults back to them without the album, but it can help.

‘She had loose photos which we then identified and put in the album.

‘I also spent time observing things in each photo and asking questions to help trigger memories too. A great way of finding more about their life too. If it’s a fun or proud time it was also great for her mood and self-worth.’

Sporadic gardener

‘It’s probably exactly what she needs – just to repeat her stories.

‘It is dementia, so it can change within an hour to something else.’

Toopie28

> **“It is dementia, so it can change within an hour to something else.”**

‘I think if you have tried diverting then stop, stop for a moment and try going with the stories.

‘Sounds easy and in truth it might not work but it is worth trying.

‘My sibling used to try and divert, and it had appeared to work well.

‘But one day when I went to see Dad, I said I would make him a coffee and he said, “Don’t be trying to distract me!” If that was me or you, we would be really put out if someone just didn’t listen.

> **“If the person isn’t responding to deflection to a different activity, the only thing you can do is change how you react.”**

‘I also think sometimes someone is trying to tell you something. I had a massive roasting from Dad not so long ago. I didn’t go, I didn’t say anything, I just listened.

‘At the end, I said I was sorry he felt that way and I wished things were different. He told me he didn’t know what was happening to him.

‘Fear, that was it, and being scared right at the bottom of it. If I had gone to make a coffee, cut that visit short, then I would not have been able to comfort him, and he would have been left with those feelings when I went home. It will depend on your person though.’

anonymous

‘If the person isn’t responding to deflection to a different activity, the only thing you can do is change how you react.

‘Can you maybe join in with the stories? Ask a few questions about the anecdotes which might at least lead her down a different narrative, just to give you a break? It doesn’t matter if it’s all just a flight of fancy as long as she still enjoys the chat.

‘Does she do this when she’s with family, or is this behaviour only with you? I wonder whether the behaviour is being triggered specifically by you – maybe as a kind of verbal self-soothing in the presence of someone she doesn’t recognise as much as she does family members?

'If it helps, this kind of thing does tend to just be a phase, but it can last weeks or months. You may just find you have to grit your teeth through it. I've had the same phone conversation with my mum every evening for several years now and it could drive me crackers if I let it. Then I think of my dad, who lives with the repetition 24/7.' **Collywobbles**

> **"I've had the same phone conversation with my mum every evening for several years now and it could drive me crackers if I let it."**

Tips to help

- Try to be patient and keep your tone level and calm.
- Is there a need behind the person's behaviour? Perhaps they're looking for reassurance? Or do they miss a person or place from the story and want to reminiscence?
- Is something triggering the behaviour – for example, does it happen the same time of day or around the same people?
- Distracting the person or engaging them in an activity they enjoy can help shift their focus onto something else.
- Try to avoid telling the person they're repeating themselves. This could be upsetting or knock their confidence.
- If the person is repeating themselves because they're nervous or anxious, a product like a fidget muff or sensory blanket may help. You could also try a favourite piece of music or TV show.
- If the behaviour isn't harmful or causing a problem, accept the person finds it comforting and reassuring, and let it be.

For our Changes in behaviour (525) and Supporting a person with memory loss (526) factsheets, see **alzheimers.org.uk/publications** or call **0300 303 5933**.

People share many ideas they've found helpful on our Dementia Support Forum – visit **forum.alzheimers.org.uk**

'This is me' is a form to record details about a person's hobbies, favourite places, achievements and more. This helps those around them to understand and support them. Visit **alzheimers.org.uk/thisisme** or call **0300 303 5933**.

Continence care

Readers review a range of products that are designed to help when a person has continence problems.

Continence problems can affect a person at any stage of dementia. Although this is common, it can be difficult to talk about and many people struggle to get products that may help.

We asked readers to tell us how they found using a range of continence care products, all available from our shop.

Cleaning and deodorising

The Mattress & bedding cleaner is one of a range of sprays from BioBreeze that use enzymes. It's designed to deal with smells and prevent stains from urine and other fluids.

'It smells fresh and clean, and helped freshen the mattress and pillows up,' says Stephanie.

SeaGirl agrees, 'It sprays easily, and doesn't leave marks on white bedding.

'It seems to make a difference and should also be useful for keeping the cover of the support cushion on my husband's chair fresh.'

She adds, 'As the aroma is quite intense and long lasting, I'm not sure I would want to use it on our pillow protectors.'

JB also says, 'It's easy to use, it has a pleasant smell and it masks other smells.

'But my mother-in-law found it too strong, so we couldn't use it regularly.'

BioBreeze's Incontinence odour & stain remover breaks down the bacteria that cause odours, dealing with them at source rather than just masking them.

'The smell is fine and it's easy to use,' says JB.

Stephanie's more forthright, 'The smell is amazing, and it gets rid of odour – we used it on our carpet.'

SeaGirl says, 'It's a clear liquid, with a fresh and appealing aroma. It leaves no marks.'

Stephanie struggled to read the label's small writing on both sprays, and found one nozzle stiff and the other slightly leaky. The price was a bit too much for her.

'If it was cheaper, I'd recommend it,' she said.

SeaGirl says, 'It seems to be effective and a little goes a long way, so I would recommend it.'

Wipes and body wash

Biodegradable dry wipes from Nilaqua are unscented and can be used all over the body.

'I like the size and they're more textured, less filmy than our regular wipes,' says JB.

'I would consider buying them, but they are more expensive.'

Stephanie says, 'They're soft to the touch, easy to pull out and a practical size.

However, she adds, 'When I used the dry wipes, lots of bits came off.'

Janet had a different experience, saying, 'They are nice and soft, and don't disintegrate.'

Nilaqua's Towel off body wash cleans and moisturises the skin without water. You apply it, massage it in and then wipe it off.

SeaGirl says, 'The wash has a thick, creamy foam. It has quite a subtle smell and left skin clean and freshened up, with no noticeable residue.'

Stephanie found it harder to remove, saying, 'I used a wet cloth to get it off.'

'It might be useful if someone is bed bound,' says SeaGirl.

'I wish I'd known about these when my friend was unable to get to the shower – she didn't feel clean even with a flannel bed bath.'

Washable underwear

As part of their wide collection of specially designed clothes, The Able Label offers underwear to help with light to moderate continence problems.

The knickers, Y-fronts and trunk boxers have built-in absorbent pads and are machine washable.

The Super Absorbent Washable Full Brief Knickers are high waisted, with a floral lace design.

'They feel good quality, are comfortable and fit well,' says Stephanie.

'The only downside is they take a while to dry after washing.'

The Washable men's incontinence Y-front brief has a sturdy elasticated waistband.

'At first glance, they seem huge,' says SeaGirl. 'Once on, they are still large and quite bulky under trousers. However, the fabric is soft and they seem well made.

'My only reservation is the drying time. They took around two days to air-dry.

'But they're more dignified than NHS-supplied products and a massive improvement over a pad in a pair of pants.'

Stephanie says £21 is a lot for underwear if you're on a budget, though you can get the VAT off if they're for a person with dementia to use.

'Assuming the stated 250-wash lifetime is accurate, they are fair value,' says SeaGirl.

Back-opening nightwear

The Able Label also offer nightwear that opens at the back, so that it's easier to put on and take off when needed.

The range includes the Jade easy-care floral open back nightdress and

Otis short sleeve cotton back opening nightshirt.

Stephanie, who tried the nightshirt, says, 'I didn't have any problems putting it on my husband.

'The style was helpful because if he needs the toilet at night, it saves having to pull pyjama pants down.

'The material is good quality, but it took a few washes to soften it.'

Stephanie thought the price is high, though this is a common issue with specially-designed clothing.

Visit **shop.alzheimers.org.uk** or call 0333 366 0035 for these and other helpful products:

- Mattress & bedding enzyme cleaner – £11.99
- Incontinence odour & stain remover – £11.99
- Biodegradable dry wipes – £4.14
- Towel off body wash 200ml – £4.35
- Super absorbent washable full brief knickers – £21
- Washable men's incontinence Y-front brief – £21
- Washable incontinence underwear (trunk boxers) – £21
- Jade easy-care floral open back nightdress – £39
- Otis short sleeve cotton back opening nightshirt – £38

Above prices all include VAT. However, apart from the first spray, you can buy them VAT free if they're for use by a person with dementia or other conditions, saving 20%. Tick the box stating that you're eligible for VAT relief at checkout.

For our Continence and using the toilet (502) factsheet see **alzheimers.org.uk/publications** or call **0300 303 5933**.

Compassion and empathy

Kerri Sparrowe says having grandparents with dementia cemented her passion and drive to work in dementia care.

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

My journey in dementia care started when I started working as a housekeeper in a dementia care home in 2019.

At the time I was studying psychology and I thought working there would go hand in hand with my studies. I've always had a passion for helping others and their mental health.

Eye opening

I didn't know much about dementia before this first job.

I thought it was just about memory problems, only affected older people and that it was an inevitability of ageing, which I now know are all myths.

I learned so much and, over time, I started think about the ways I could help residents with dementia.

It became clear to me that this was more than just a job – it was my calling.

Family experience

Having lost two grandparents to dementia, I understand on a deeply emotional level how difficult it can be to watch loved ones change in ways that are out of our control.

Starting at the care home coincided with my nan being diagnosed.

Having this experience affected my work life. I saw things from not just the perspective of the person with dementia, but how it can affect their family and those around them.

I used what I learned in my job to help my nan too.

We tried robotic pet therapy at work and I managed to get a robotic dog for my nan, as she used have a Westie. It was a great way to build a connection with her and we saw her regain a sense of purpose from it.

When I'm caring for our residents and speaking to their families or friends, I often think about my nan. If it wouldn't be good enough for her, then it's not good enough for anyone.

Recognising the person

The smallest of gestures can make a big impact for a person with dementia, even if it's just a smile or a hug, remembering their favourite song and how they like their tea.

It's important to recognise the person behind the dementia. I always say you can't bring them into our world, we have to go into theirs.

Everyone has a rich, meaningful life that deserves recognition.

I've worked my way up to my current role as Care Needs Coordinator and Dementia Lead at Haviland House in Worthing.

This job involves care-planning for the residents, as well as training staff. I want to foster a compassionate environment, that's my guiding principle.

Using my platform

I want to use my platform to raise awareness of dementia and contribute to change in the way we approach dementia care.

Sometimes dementia care can be clinical and task orientated.

I'd like to see a balance of emotional and psychological support, and for all health professionals to receive training in person-centred care.

What drives me every day is knowing that I'm helping people maintain their dignity, quality of life and autonomy, even as they face challenges.

This job has had a profound impact on me personally.

It has given me a greater sense of empathy and understanding, and purpose.

My work has also helped me process my own feelings of loss and grief from losing my grandparents.

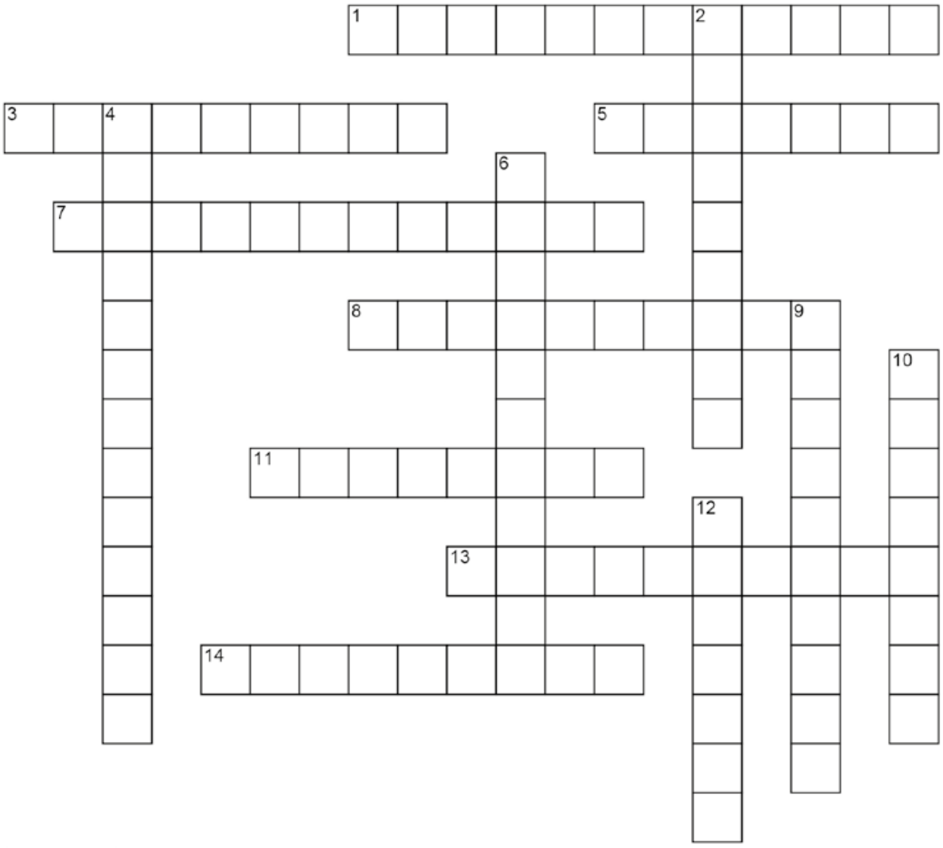
There's solace in knowing, even in the most difficult moments, that I'm part of a team helping people going through similar struggles.

Puzzles

See page 38 for answers to last issue's puzzle

Anagramword

Summer has truly arrived with Pete Middleton's latest puzzle! Each clue begins with words that are an anagram of the answer, along with a clue to its meaning. How many can you solve?



ACROSS

1 Modern truths reveal a regular UK summer weather event (12)
3 Cures babe by providing outdoor meals (9)
5 Old hay I enjoy for a couple of weeks in summer (7)
7 A clerk's bribe can be picked from a hedgerow (12)
8 In odd lanes, there are weeds that might make you wet the bed! (10)
11 Teams too are grown to provide salad food (8)
13 Racier tone provides a word to describe fun summer activities (10)
14 Cats issue us a means of packing for travel (9)

DOWN

2 Swab a doll to make a container for a summery side dish (5,4)
4 Collate errors to provide a common fairground attraction (6,7)
6 Ill words few use to describe the colourful contents of a meadow (11)
9 Spin in glee when you aren't having to get up early (8,2)
10 Past news that may contain stinging content (4,4)
12 I signal when out on the water under canvas (7)

Brain workout

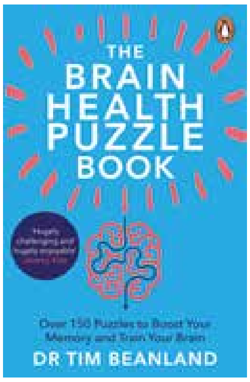
Have you tried our Brain Workout puzzle packs?

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.

150 puzzles

The Brain Health Puzzle book features 150 puzzles of varying difficulty that challenge memory and skills with pictures, words, numbers and logic. Available for £10.99 from our shop – visit **shop.alzheimers.org.uk** or call **0333 366 0035**.



Competitions

Send us your competition answers with your name and address by end of 7 July – email magazine@alzheimers.org.uk or write to the address on page 2.

Hygiene sprays

We have a full set of BioBreeze sprays to help clean and neutralise odours (see pages 34–35) for one lucky winner drawn from correct entries, and Incontinence odour and stain remover sprays for 10 runners-up.

Q: BioBreeze sprays use enzymes to:

A. Digest their lunch.

B. Eliminate odours and stains.

C. Brew and ferment beer.

Forget-me-not seedballs

We have a Forget-me-not seedball tube for two winners drawn from correct entries, and Forget-me-not seedball boxes for five lucky runners-up.

Q: These forget-me-not seed balls contain chilli powder to deter:

A. Gardeners from using their hands to plant them.

B. People who don't like spicy food from enjoying the flowers.

C. Slugs and snails from eating the young shoots.

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.

April/May winners and answers

Simple music player

F Crawford in County Tyrone won a Simple music player and M McIlwain in County Down won Take Note cards. Answer: The Simple music player is designed so that you can start and stop music by lifting and closing the lid.

Trek26 goodies

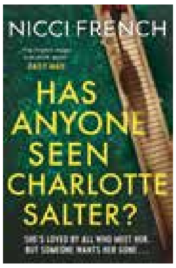
G Wright in Hertfordshire won a water bottle and headgear, while an anonymous reader in Greater London, A Smith in East Sussex and A Aspell in Isle of Man each won a tote bag. Answer: Locations of Trek26 challenges this year include Stonehenge, Eryri (Snowdonia) and Northumberland Coast.

Book giveaway

P Hubbard in Worcestershire, R Carden in Gloucestershire, Jools in Suffolk, A Hanscomb in Wiltshire and A Cross in Orkney each won a copy of The Memory of You, by Samantha Tonge.

Anagramword

Across: global warming, cloud, hailstorm, barometer, tsunami, climate, greenhouse, heatstroke. **Down:** floodplain, rainbow, dewpoint, hypothermia, thermometer, anemometer, satellite, typhoon.



Book giveaway

See page 21 for a chance to win a copy of Has Anyone Seen Charlotte Salter? by Nicci French.

Coming up

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

A huge thank you to the Young Dementia Thematic Group, who planned and created this special co-produced June/July issue with us! Expect to see noticeable changes in future issues as we draw on their brilliant ideas.

In our next podcast, out in early June, Antonia Kanczula finds out more about the Bentham Line (see pages 22–23). Listen at **alzheimers.org.uk/podcast** or search 'Alzheimer's Society' on your podcast app.

Our August/September issue will be out at the start of August, and we're looking forward to sharing interviews with one man with dementia determined to stay active with his family's support, and with another who's involved in creating a football-themed play.

We'll also have articles about Sahara – our support service for South Asian Communities in Greater Manchester – and about the incredible work coming out of our partnership with Cadent Gas Distribution Network.

Your ideas

Email us at **magazine@alzheimers.org.uk** or write to the address on page 2.

When to step in?

For a future article, we'd like your tips about deciding whether to help a family member or friend who has dementia to do something.

- Have you felt uncertain about whether helping the person too much means they're not keeping the skills they have?
- Maybe you've regretted being too ready to step in to do something for them because you've realised they still want to do it themselves?
- Perhaps you've wondered if they would appreciate more help but don't feel able to ask for it?

Please share your tips before 3 July.

New activities

One idea from the Young Dementia Thematic Group we weren't able to organise for this issue, is an article where people share their experiences of trying out a new activity. It could be anything from circus skills to aromatherapy. What activity would you like us to cover in this way?

Readership survey

We always welcome your feedback about the magazine, but we're especially keen to know what you think of this special June/July issue.

Take part in our readership survey before the end of July – let us know if you didn't receive yours, or complete the online survey at **tinyurl.com/dementiatogether**

Enter your poems

Our eighth poetry competition remains open to entries until midnight on 30 June.

You can enter up to three poems that you've written about dementia, or about people affected by the condition. Each poem can be up to 30 lines long.

We'll recognise poems that express the impact of dementia, as well as those showing the greatest skill with words.

Winning entries will be published in our October/November magazine (you'll retain copyright of your work).

Please email your poems to **poetrycomp@alzheimers.org.uk**
or post to: **Poetry Competition,
Alzheimer's Society, Suite 2,
1st Floor East Wing, Plumer House,
Tailyour Road, Plymouth PL6 5FS.**

If there's another way you'd like to enter your poetry, please let us know and we'll see what we can do.

The competition is open to residents of the UK, Republic of Ireland, Isle of Man and Channel Islands who are aged 16 or above at the time of entering.

Poems must be your original work and not published elsewhere (unless in a personal capacity, such as on your blog – ask us if you're unsure).

If poems are entered on someone else's behalf, the person entering them must have the poet's permission to do this before entering them into the competition.

Poems will be anonymised while being shortlisted and winners selected, and the results are final.

Alzheimer's Society

Memory Walk

It's not just a walk.

It's thinking about those we love.

And building a better future.

Together, we can stop dementia devastating lives.

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

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