

Dementia together

October/November 2021
Alzheimer's Society's magazine

Open again

Much-missed support

A friend at home

Homeshare benefits

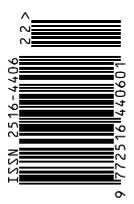


Passion to educate

Challenging perceptions

Also in this issue

Social care cap
Music and radio
LGBTQ+ resources



A full life

Rich and unique memories



Welcome



We're immensely proud to publish six wonderful winning poems in this issue of the magazine (see p20).

The number of people who took part in our competition is testament to the power of poetry and the great desire among our readers to say something, do something to share what they've lived and make others' lives better.

We thank every single person who took pen to paper (or fingers to keyboard) and sent us their poetry. We also thank our shortlisting panel, who read hundreds of deeply affecting poems, and our judge Vahni Capildeo, who picked the winners. They were all hugely generous with their time as well as with their invaluable mix of perspectives, understanding and insight.

And that's only four pages of this magazine! The rest, as ever, is full of the real-life stories and ideas that we know can make such a difference. If you have a story to share, or a comment or suggestion about the magazine, please let us know using the contact details below.

Danny Ratnaike, Magazine Editor



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Need support? We're here for you – see p8.

Dementia together is the magazine for all Alzheimer's Society supporters and people affected by dementia. Contact us on magazine@alzheimers.org.uk, 020 7264 2667 or 020 7423 3676.

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Using our influence: NI and Wales

Alzheimer's Society is attending party conferences in Northern Ireland (NI) to garner support to implement the Regional Dementia Care Pathway – a vision for high-quality dementia services. Starting with the Ulster Unionist event, with health minister Robin Swann and other key assembly and local government figures, these are great opportunities to push for dementia to be prioritised in the ongoing reform of adult social care.

Alzheimer's Society Cymru has been meeting with the government, NHS, charities and people affected by dementia about raising awareness of the condition in Wales. Held during World Alzheimer's Month in September, discussions focused on the importance of reaching a range of communities, and how resources could be shared.

Cap too high for most

Alzheimer's Society, while welcoming plans for new social care funding, has warned that a proposed cap on care costs in England won't make a difference for most people affected by dementia.

In September, the Prime Minister announced UK-wide taxes to pay for a £86,000 cap on the most a person needs to pay for personal social care in England. Details of how this may affect some people but not others are still to be confirmed, but the value of assets that someone needs to have before they start paying for care will also rise to £100,000. The changes would mean that they'd need to pay until they either reach the cap on costs or until their assets are down to a value of £20,000.

The taxes come into force from April 2022, but the cap and asset limits will only be introduced from October 2023. From money raised by the new taxes, £2.2 billion will go to Wales, Northern Ireland and Scotland administrations.

Fiona Carragher, our Director of Research and Influencing, said, 'A cap would need to be considerably lower if it's to make a difference for more than a handful of people with dementia.

'We are also concerned about the distribution of the funding. Social care must be treated on equal footing with our world-class NHS if we are to see real change.'

The Society recently released *Stabilise, Energise, Realise* – a report setting out a 10-year plan to fix social care, including detailed recommendations to improve the quality of care for people with dementia. We are discussing these calls with MPs at Labour and Conservative party conferences this autumn.

Progress has been made thanks to people like you – join us at alzheimers.org.uk/campaigns

Helpful products: Your ideas

We want your opinion on products and technology that could help people affected by dementia in their daily lives.

Our online shop is always looking to improve its wide range of products that help people to live better and longer in their homes, including telephones, clocks and home safety devices.

We're now looking for your ideas about what people would find helpful, and your comments on other people's ideas, through Alzheimer's Society's Innovation Hub.

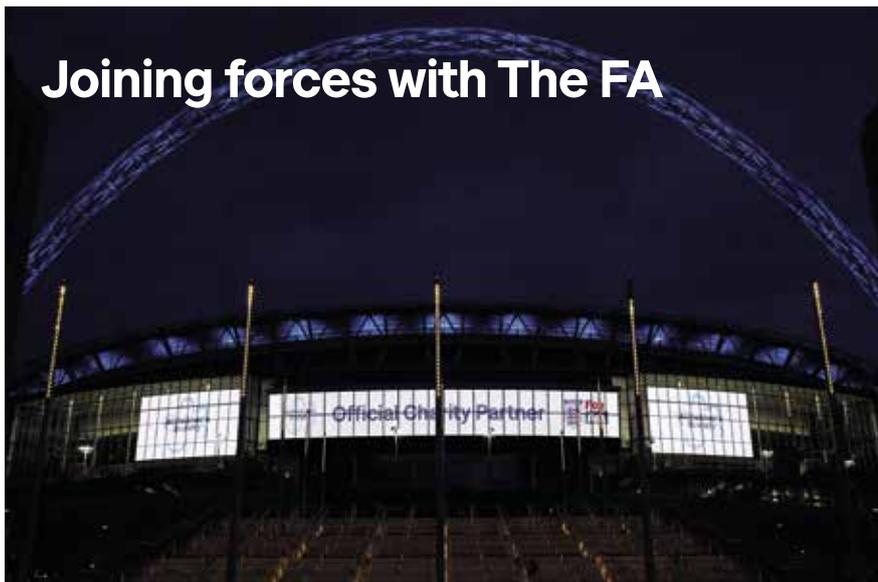
Sign up to our Innovation Hub at innovationhub.alzheimers.org.uk to share your ideas.



Elf Day is back!

Unleash your inner elf to raise money for people affected by dementia this December – from fancy dress to festive bake sales, anything goes! Sign up today and receive a free inspiration-filled fundraising pack, whether you want to celebrate Elf Day on 3 December or another date. Sign up at alzheimers.org.uk/elf-day

Joining forces with The FA



Directions

My winter woollies are definitely back in circulation – where did the summer go?!

As the year marched on, so did you! Our Memory Walks were especially joyous this year, bringing so many families and friends back together to celebrate but also remember loved ones who were lost over the pandemic. A huge thank you to everyone who got involved by walking, raising funds and volunteering.

I have loved being able to get out and about at long last. A visit to one of our phone hubs, in Warrington, gave me an opportunity to hear more about calls to our support line. A gentleman worried about an older neighbour who seemed to be deteriorating quickly and a family still struggling to visit a relative in residential care were both helped by our expert staff while I was there. I've also visited teams of dementia advisors who are delighted to be back working with people face to face, offering the in-depth emotional support that so many need.

As we move into winter, I am nervous to say too loudly that things slowly seem to be getting back to normal for Team Alzheimer's Society, and long may it continue!

Next, we need to ensure anyone worried about their memory is able to get an accurate and timely diagnosis, as sadly diagnosis rates are still very low. As with all our work, it's your involvement and support that makes the difference – thank you.

Chief Executive Officer
[@KateLeeCEO](https://twitter.com/KateLeeCEO)



Photographs: Getty Images/The FA

(Clockwise from left) Manchester City's Jack Grealish and Riyad Mahrez and Leicester City players all sporting our shirts.

Alzheimer's Society has partnered with The Football Association (FA) to use the power of football to change the lives of people affected by dementia.

The two-year partnership will raise awareness of dementia as well as significant funds for our support services, such as the Dementia Connect support line.

Together, we will break down barriers so that no football player, former player or fan faces dementia alone.

The partnership was launched at the Community Shield game in early August, where Leicester City and Manchester City players wore specially branded T-shirts before the game. It will work alongside our pioneering Sport United Against Dementia campaign.

Find out more about Sport United Against Dementia at alzheimers.org.uk/SUAD

In the press: Diagnosis by AI

An artificial intelligence (AI) program designed by University of Cambridge researchers aims to diagnose dementia with a single brain scan. This was widely reported across media outlets in the summer, but what does this technology offer?

The AI compares brain scans of people at risk of dementia with thousands of confirmed cases, to identify similar patterns of brain changes that even the most expert human eye can't detect. When this program was tested, it was sometimes able to diagnose dementia from a scan done years before the person experienced symptoms.

It will now be tested in some memory clinics to see if it could be used more widely. If successful, the technology may help improve the accuracy of dementia diagnosis.

Clare Jonas, Research Communications Officer at the Society, said, 'Although AI methods for diagnosing dementia have been tested before by researchers, they tend to classify people with mild thinking and memory problems into groups. For example, "problems are expected to get worse" or "problems are not expected to get worse".

'This means people could be wrongly classified and may not have the opportunity to access the right treatment or support, or to take part in trials for new drugs at the time they're most likely to be effective. The new approach makes a more personalised prediction.'

Find out more about taking part in dementia research – call 0333 150 3456 and ask for the Join Dementia Research helpdesk or email joindementiaresearch@alzheimers.org.uk

Extra research funding needed

A new report has called for the government to bring forward proposed extra funding for UK dementia research.

The government made a commitment at the 2019 general election to introduce a 'Dementia Moonshot' that would double its dementia research funding over the next decade.

Over the summer an inquiry was held by the All-Party Parliamentary Group (APPG) on Dementia, a cross-party group of politicians run with support and advice from Alzheimer's Society.

They heard from leading researchers, academics, research organisations, charitable funders and people affected by dementia about how this extra £800 million could be best used.

The report, titled Fuelling the Moonshot, also makes recommendations on how to increase participation in research and how to better support researchers who are earlier in their careers. **For the full report, see alzheimers.org.uk/appg**

LGBTQ+ Advisory Group

The LGBTQ+ Dementia Advisory Group is made up of people affected by dementia and professionals who are passionate about improving the lives of people affected by dementia who identify as LGBTQ+ (lesbian, gay, bisexual, trans and queer). It meets online every month to share ideas, resources and networking opportunities. To get involved, email lgbtq.dementia@gmail.com

Accessible bank cards

We have helped HSBC UK create a range of accessible bank cards for people with dementia and other conditions. Arrows, raised dots, larger fonts and contrasting colours all make the cards easier to use.

Morven Lean, our Senior Strategic Change Manager, said, 'These accessible cards are an important step to ensure people living with dementia feel supported and treated as equal members of society.'

Annual conference: Save the date

Take part in discussions to improve dementia diagnosis and support at the Alzheimer's Society Annual Conference 2022 and hear the latest about key issues.

As well as people affected by dementia, professionals and policy makers will attend the conference in London on 17 May, during Dementia Action Week.

Register your interest now at alzheimers.org.uk/conference

CHC appeal support

Challenging a decision to refuse or withdraw an NHS continuing healthcare (CHC) package can be difficult and complex. We have a small team of experienced volunteers who can provide support with this.

For more information, email NHSCC@alzheimers.org.uk or call 0333 150 3456.

Local profiles

The Society has created a Local Dementia Profile for each city and county in England, with key actions for local authorities to support people affected by dementia, examples of good practice and statistics about dementia for that area. These profiles will be updated every six months.

We've also released a series of reports with recommendations for how local authorities and NHS services in England can increase the number of people with dementia who receive a diagnosis. These address the reasons for different diagnosis rates across the country, and the barriers faced by minority ethnic communities and people in care homes and hospitals. To help influence change in your area visit alzheimers.org.uk/influencing-local-government



Updated memory handbook

We've updated our booklet for people with mild memory problems – The memory handbook. It includes ideas to help people cope with memory problems and live well. The updated version contains more information about helpful technology as well as additional relaxation techniques.

For The memory handbook (1540) booklet, visit alzheimers.org.uk/memory-handbook or call 0300 303 5933.

Landline changes

We're raising concerns with industry leaders, including regulator Ofcom, about plans to switch off the technology that powers landline telephones in 2025.

UK homes will move from traditional copper-wire to internet-based landline connections, and we want to prevent people who don't want the internet being excluded from services. We're also pushing for people affected by dementia to receive the highest levels of support throughout the switchover.

In the meantime, we advise anyone with a personal or other alarm that uses a telecare system to speak to the company that provides the telecare service.

Your own Singing for the Brain

We're offering support and resources for people to run their own Singing for the Brain group for people affected by dementia. This could be done by care providers, other organisations or individuals with an interest in music.

To find out more, visit alzheimers.org.uk/singingforthebrain



Don't miss...

Tommy in Liverpool, who has Alzheimer's, says he never thought he'd be competitive again... until the Home Games! [See p 12.](#)

Courtney in Flintshire shares the joy Elf Day brought last year, and her hopes for this December. [See p 13.](#)

Emma in Sunderland is helping fellow healthcare professionals improve how they support people with dementia. [See p 14.](#)

Meet Alex, Public Affairs Officer, and Sube, one of our trustees. [See p 18 and p 19.](#)

Our Dementia Resource Centre in Peterborough has reopened to the delight of local people affected by dementia. [See p 28.](#)



We are here for you

Phone support

Our dementia advisers are available on the phone seven days a week, providing information, advice and emotional support to anyone affected by dementia.

Online support

Find a wide range of information on our website to help you understand and live with dementia. Visit our online community Talking Point to connect with others in a similar situation and search for local support services on our dementia directory.

Face to face support

Some face-to-face support services are reopening. Where it is safely available, our dementia advisers will connect you to relevant face-to-face support in your area, from one-to-one advice services to local support groups.

Contact us today

0333 150 3456

[alzheimers.org.uk/getsupport](https://www.alzheimers.org.uk/getsupport)

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21065SD

**‘No matter what
you’re going through,
there is someone who
understands. I don’t
feel alone now.’**

Person living with dementia



A full life

Connie Hall has enjoyed a varied life full of rich and unique experiences. Gareth Bracken speaks to a woman with dementia who has no time for hate.

Connie Hall remembers the moment in the mid-1950s that her then-husband suggested they move to England from their home in Grenada, in the Caribbean.

'My daughter was being christened and somebody said they're asking for people to come to England to work,' she says. 'I said to my husband that it was a good idea, but our daughter is only a few weeks old. I'm not leaving my kids to go anywhere!'

Connie, who is 90 in November, made the move to Middlesbrough a year later, and now lives in Chiswick in west London. She has four children, 11 grandchildren and many more great-grandchildren, as well as a lifetime of stories and experiences.

However, her dementia diagnosis and worsening memory have also brought sadness, worry and many challenges.

Nice people

Some of Connie's strongest memories from her life in Grenada are of the people she grew up around.

'I can't forget the people in my young days, they were very nice,' she says. 'Everybody was nice to each other, there was no swearing. They would help each other, nobody ever said no. My neighbour's kids went to the same school as me, so she'd pick us up. There were very nice people in those days.'

Connie also remembers spending hours working in the garden.



'I miss my garden terrible,' she says. 'I really loved gardening.'

Her family owned farmland and animals, including cattle and goats, and grew their own produce.

'We didn't buy food, we just grew it ourselves,' she says. 'We had mango trees and grew watermelon and a lot of bananas. The only food I didn't like was breadfruit.'

On the buses

Connie arrived in England with her two children around 1957, in her mid-20s, following her husband who was working in Middlesbrough as a motor mechanic. They later had two more children, both born in England, including daughter Sharon, who now lives with Connie.

'Middlesbrough was wet and cold! Especially at nighttime,' says Connie, who found work through a contact of her husband's.

Quick read

Connie Hall, who's 90 in November, can look back on a lifetime of memories from Grenada to Middlesbrough and London.

Connie was diagnosed with dementia a few years ago, and her daughter Sharon says her symptoms worsened since lockdown.

Alzheimer's Society put Connie in touch with volunteer Sue, who kept in contact by phone when the pandemic stopped visits.

Summing up her values, Connie says, 'I haven't got time to hate anybody.'

‘He was working with a fella called Tony, who asked me what did I do when the kids go to school,’ she says. ‘He asked me if I could make tea for the people waiting to buy cars. I did that for a long time.’

Connie later saw an advertisement for people to work on the buses.

‘I thought, “I’d love to be a bus conductor!”’ she says. ‘People were thinking that I wouldn’t do it, but I applied, went for the test – oh blimey, I can see myself now!’

Street attack

Although many people in Middlesbrough were nice to her, Connie and her family also experienced a lot of racism.

‘My husband used to go to work at night, and a load of young boys grab him to fight. I’d never forget that,’ says Connie, who recalls other young white people stepping in to help.

‘They said, “That’s Mr Hall, leave him alone!”’

Connie’s daughter Sharon says she had a ‘horrible’ time at school, while Connie also remembers the reaction of her new colleagues when she went for her bus conductor training.

‘You see people pulling their hands away,’ she says, miming the action of someone drawing their arms back sharply.

Connie developed good relationships with her colleagues and was even featured in a local newspaper article in the mid-1970s.

‘They came to my house and asked me a lot of questions,’ says Connie, who didn’t give too much thought to being the only Black employee. ‘I never used to look at it that way,’ she says.

Connie and Sharon also remember the Middlesbrough FC team coach breaking down near their house, and some of the players coming in for refreshments while new transport was arranged. Among the group was the famous Jack Charlton, manager of the team.

‘I remember that man, he sent a present for me,’ says Connie. ‘I don’t know much about football, because in Grenada they play cricket.’

London life

Sharon later moved to London, and Connie followed, living in Northolt in the west of the city. She worked in catering for the police, in station kitchens in Hounslow, Ealing and Chiswick.

‘You’d order the stuff, price the stuff, you have to do the bookwork. I liked it,’ she says. ‘The police would sometimes pick me up or take me home.’



Photographs: Derek Goard

Use your experience of dementia to help shape our work – visit [alzheimers.org.uk/dementiavoice](https://www.alzheimers.org.uk/dementiavoice)

More recently, Connie has enjoyed some other celebrity encounters, meeting politician Ken Livingstone at an event at Kew Gardens, and Mayor of London Sadiq Khan through another organised by Alzheimer's Society.

Fast and furious

A few years ago, Connie was diagnosed as being in the early stages of dementia.

'Lately, I forget things quite a lot,' she says. 'The doctors say I have dementia, but nobody can tell me what caused it.'

Connie says she forgets things like names and places, while a strategy to help her remember hasn't worked so well.

'I write down somebody's name on a piece of paper, but I forget about the papers!' she says.

Connie says it can be difficult talking about her dementia.

'It's a bit sad to think about – I get maybe a bit sad about it,' she says. 'You forget this and you forget that.'

Sharon says that Connie's dementia has been 'worse' since

lockdown and 'wasn't this bad before'. She says it is affecting Connie's behaviour as well as memory.

'She thinks the TV can see her, so she won't get dressed or undressed in front of it,' says Sharon. 'There have also been a few violent outbursts, and once there was really bad confusion – you could feel it.'

'It's getting fast and furious now, which is sad, because she's so physically fit for 89.'

Favourite song

Connie used to regularly attend local Age Concern groups, which stopped during the pandemic.

'People there are laughing and having jokes and things like this,' she says. 'When they ask what would you like to hear, I say Oh Carolina – my favourite song. But I haven't been there for a long time now.'

Connie also went out and about with volunteer Sue, who Alzheimer's Society put her in touch with. During the pandemic Sue has kept in regular contact by phone, which Connie has enjoyed, particularly as she doesn't feel so confident about leaving the house at the moment.

'Because of the thing we're in now – the COVID – I don't fancy going out,' says Connie, who has had both of her COVID vaccinations.

Extra help

Sharon is her mum's main carer, and Connie acknowledges her support.

'Sharon do everything!' she laughs. 'I need the extra help. The worst was the kettle – I burned the kettle on the gas. It makes me worried.'

Sharon also supports her sister, who has a brain injury, though she won't leave Connie on her own for too long.

'The social workers said they'll give someone to sit with Mum, but it hasn't happened yet,' says Sharon. 'I don't think you get enough help to look after someone.'

Asked how she feels about her life now, Connie immediately thinks of her old friends who have sadly died.

'Life is OK. That's all I can say. What can I do?' she says. 'The three best friends I have are gone.'

As she reflects on her many achievements and rich experiences, Connie shares one of her most important values.

'I'll never say I hate this person, or things like that,' she says. 'I haven't got time to hate anybody.'



See [alzheimers.org.uk/dementi DIRECTORY](https://www.alzheimers.org.uk/dementi DIRECTORY) to find support near you.

Donate

You can keep people diagnosed with dementia in touch with the support and help they need.

Donate now.

Home Games

Tommy Dunne in Liverpool, aged 68 and living with Alzheimer's, tells us about taking part in a 'home Olympics'.



The Home Games was an opportunity to bring people with various long-term health conditions together in a 'home Olympics', all on Zoom.

The training gave me a sense of purpose during lockdown, and it bought out the competitiveness! I never thought I'd be competitive with other people again. Your team relies on you and your discipline.

It was absolutely amazing to be part of it. I felt like a part of society again – contributing to a team again.

Feelgood factor

You trained for every event, and you had to do two disciplines as part of the final. It's the taking part that counts but winning always helps, it brings that out in you!

'Baked Bean Can Do' was lifting bags of cans of beans, and 'Step Ascent' involved foot-high step-ups. 'Pillow Javelin' was throwing

a cushion from one end of the garden (I caught the top of the fence – luckily it didn't go into next door's).

The 'Plant Pot Hurdles' were made from flowerpots and canes. Four laps of that up and down the garden. I was up against a 30-year-old and I didn't lose – it was a dead heat!

Every week before the final, Paralympians Lauren Rowles and Sarah Storey trained you in different disciplines. I was amazed at how fit you can get just doing those short exercises. It released that feelgood factor and endorphins lifted your spirits to give you something to look forward to for the next week.

Lauren and Sarah were so inspiring. To think they've done the real thing – it gives you a sense of the training they must go through, the energy every single day to get to the level they are.

Change perceptions

I want to take the fear out of dementia, change the perception that people with dementia can't learn anything new. We've got to have something to get out of bed for, to have a purpose.

Physical activity is a must for us. Your body has got to be healthy to help your mind. Get up, go out, go for a walk. You can still play golf. Watching football is taking part, gets the adrenalin going, being socially engaged with other people – talking about old games is great.

With dementia, you've got to work twice as hard just to stand still. If you stop, you're going to go backwards.

The Home Games gave me an opportunity to see other people's abilities. I don't see their disabilities, I see what they do and what they can do.

The pandemic has given society a taste of what social isolation is like. People with dementia don't need sympathy, we need empathy and support.

The Home Games was part of We Are Undefeatable, a campaign supporting people with a range of long-term conditions, including dementia. For more about the campaign and ideas to get moving, visit alzheimers.org.uk/active

Positively elfy

Courtney Jones in north Wales remembers the joy that last year's Elf Day brought to colleagues and the people they support.



I'm Admin Assistant/Care Co-ordinator at Liberty Care Flintshire. We provide carers for adults who need support at home, including specialist care for people with dementia.

We saw a post about Elf Day on the Alzheimer's Society Facebook group last year, and we put it on our own group chat. Everyone seemed well up for it, people were jumping on the bandwagon, throwing ideas in – they all wanted to participate!

Like family

During lockdown, we noticed a massive increase in people feeling isolated and lonely, not seeing their families. About 70% of our clients have dementia, and our carers are very attached to them – they're more like family.

Alzheimer's Society also means a lot to me, as my gorgeous Nanna Ffrith has dementia.

It's been a gradual process for her, and for our clients who have dementia. It's the initial diagnosis first, and it's hard to think about what's next – you're going to notice a deterioration.

One day you'd go there and my nan will remember you and talk about old days. Then you'd go and get a cup of tea and she'd say, 'Who are you?' It's affected me and other members of our family.

It helps to be positive, and we wanted to spread positivity.

Fun-filled day

We did a few things for Elf Day, though we were limited due to pandemic restrictions. Staff dressed up as elves when visiting clients. They were howling with laughter when staff walked in!

A colleague made about 30 boxes of elf-themed cupcakes, a box of 12 for £6. We also had a Secret Santa and Guess the Name to win a really big elf toy, choosing from 40 Christmas-themed names.

We raised over £500, and clients made donations too – Alzheimer's Society is a good cause that's helped them in the past.

It was a fun-filled day, so different to what we were experiencing last year. Next time we want to do it bigger and even better!

Unleash your inner elf for Elf Day on 3 December (or another day that's convenient for you) – see alzheimers.org.uk/elf-day or call 0300 222 5770.

Quit for a bit



This November we're challenging you to quit sugar, alcohol, or take on the ultimate challenge and give up both. The money you raise will help us continue to be there to support people affected by dementia.

Sign up today at alzheimers.org.uk/quit

Irish memories

Cuimhne Carers Project supports people caring for an Irish relative who has dementia. They provide links to reminiscence advice and resources, as well as a range of informative and practical webinars and videos.

See www.irishinbritain.org/cuimhnecarers



Become a Dementia Friend

Dementia Friends learn about dementia so they can help their community. You can become a Dementia Friend by taking part in an online session, and also by watching our online videos.

Visit dementiafriends.org.uk to get involved.

Better prepared

Emma Boxer, a Dementia Friends Champion in Sunderland, shares how better understanding of dementia is helping her work as a pharmacist.



I finished university at the University of Sunderland and was in my pre-registration year – where you work as a pharmacist but are supervised – when I first started working with people who have dementia.

I felt underprepared. I understood the medications but, on a holistic level, didn't feel I was equipped. I wanted to put something in place for other students to address that.

I spoke to the university about doing Dementia Friends sessions and they were very keen. I did sessions for pharmacy, nursing and public health students. I also did some sessions at local care homes for staff members and residents' relatives.

Big impact

When I left university a couple of years ago, I'd created over 300 Dementia Friends. I've been back twice since every year, so it's probably about 400 now.

Every year I come back and teach the new cohort of students. This year they had to move online because of the pandemic, so I made a pre-recorded video which was played to the students. I imagine next year's sessions will be back to being face-to-face.

I ran a brief survey asking about people's understanding of dementia before and after my sessions. The feedback was really positive – people said that their knowledge increased and that they felt better prepared.

People say it makes a big impact when healthcare professionals are helpful, kind and patient to people with dementia, so it's really important to keep this going with the next generation of students coming through. It's worth spending that time to make sure people know how to do it correctly.

Take the time

I'm Lead Pharmacist at Sunderland Royal Hospital, and as outpatient pharmacists we do see patients with dementia. There's no cookie-cutter version of what a person with dementia is. It's important to take the time to get to know them as a person and what works for them, just like you should for any patient.

Improving my knowledge of dementia has definitely helped me as a pharmacist. Someone might

have just received a dementia diagnosis and been prescribed medication, or been for a review and received new medication. I prepare the medication and go through any concerns or worries the person might have.

People with dementia have suffered a lot during the pandemic. Patients who would have been referred to face-to-face services before might not have been getting as much of that, so it's really important now to make sure that everyone gets the support they need.

Find out more about being a Dementia Friends Champion – see dementiafriends.org.uk

Meet the researcher: Katie Gambier-Ross

Research Fellow and PhD candidate at the University of Edinburgh.



Favourite things?

- Book – Slaughterhouse-Five by Kurt Vonnegut.
- Way to spend time – In or on the ocean!
- Memory – Spending summers in my hometown of Kinsale, Ireland, with friends and family, sailing and swimming in the ocean. One day in particular stands out in the summer of 2013 that my friends and I still refer to as ‘boat day’.

Why dementia research?

Mom was a dementia specialist nurse and I saw first-hand how her work brought her, and the people around her, so much joy and fulfilment.

I chose to work in dementia research because there are so many misconceptions about dementia. By better understanding people’s lived experience, we can tackle stigma and discrimination, and enable people to lead lives of meaning and purpose regardless of their diagnosis.

How has Alzheimer’s Society supported your work?

Alzheimer’s Society funded my PhD studentship, which began in September 2017. My research aimed to understand the experiences of ‘going out’ for people with dementia and carers – including finding their way, getting lost and being reported missing.

Through walking interviews, traditional interviews and group discussions, I found that people were still very active and engaged in their local communities and that being able to go out was important for their wellbeing. I also documented challenges that people face when navigating, and the strategies they use to overcome and avoid these.

What are you currently working on?

I am working on getting my PhD research out into the world so it can be useful! One way I plan to do this is

by producing a guidebook based on my PhD findings. This could be used by search and rescue teams when people with dementia are reported missing.

What difference do you hope this will make?

As well as helping searches, I hope my PhD research will encourage other researchers to consider more creative and innovative methods, such as walking interviews.

I also hope my research will add to the new and growing body of research known as ‘critical dementia studies’, which examines the diversity that exists among people living with dementia.

In what direction would you like to take your research in future?

The people who participated in my PhD research were all so unique and they taught me that, despite living with dementia, it did not define them.

I would like to learn more about how people’s experiences of dementia intersect with their experiences of gender, sexuality, ethnicity and socio-economic status. This could be used to ensure that dementia policy and practice are as inclusive as possible.

Donate

Your donation funds increasingly important research, only possible with your help. [Donate now.](#)

How I stop and reflect

We ask people about how they keep active and well, whether they have dementia or not. This issue, we hear about reflection and being mindful.

Pauline Howl, 64

Reflection on life and what it means to be alive, and how people manage their lives when they have to live with disabilities. This can be done at any time, eg in a queue in the car, whilst gardening or walking in the local park. It tends to be a solitary activity, however sometimes I will share my thoughts with family or friends.

Agnes Houston, 73 in North Lanarkshire with Alzheimer's



When I was diagnosed with dementia, in the 'dark ages', it was a negative place. I went to yoga! It wasn't easy at first and I persevered with it, they persevered with me, and we grew together.

My dementia caused sensory issues and I have other long-term conditions that make breathing difficult. Yoga has taught me breath work, complementing my medication. I have difficulties sleeping at night, so practise mindfulness. This benefits me both physically and mentally.

Yoga and mindfulness have given me my own Mary Poppins tool bag!

Yoga and mindfulness have given me my own Mary Poppins tool bag!

Sarah Williams, 56 in East Sussex

I suffer from severe depression and anxiety, and find that keeping a diary and writing down my feelings for the day helps a little to keep a lid on things.

Some days it does help and some days it doesn't, but I feel like a weight has been lifted just by writing how I am feeling down. It allows me to look back and see how I coped with my feelings on a particular day.



Lynne Parry, 69, Cornwall

I'm writing up my life history, keeping separate files of different stages in my life

and adding to them as I remember events from that time. It's reminding me of so many events and providing a memory of me for my sons and grandchildren.

Taking part in Action for Happiness offers a daily activity to boost my mood. It's given me daily simple pleasures to warm my day – see www.actionforhappiness.org

Susie Mackenzie, 68 in York



I practise mindfulness and keep a daily journal reflecting how I feel each day when I wake up, my practice of

loving-kindness meditation (which I do first thing) and then how I feel when I go to bed.

I started using mindfulness when my mother had dementia. We both became calmer. I stopped responding to her frustrations and anger, instead I would take three breaths, notice my reactions and

then ask her to explain how she was feeling. I started accepting her as she was, not as I wanted her to be. I also began to be more comfortable with my feelings of loss and frustration.

Katherine Ripley, 55 in South Yorkshire

I used a mindfulness phone app daily to get me over a particularly difficult period, and now use them on bad days. It enables me to focus on the present moment, and stops racing and ruminative thoughts which can result in anxiety building.



Stay well

Some things, like age and genes, affect your chance of developing dementia but you can't change them.

Things you could do include keeping your mind and body active, enjoying healthier food, not smoking, drinking less alcohol, staying in touch with people, and dealing with any health problems.

If you already have dementia, the same things can help you to stay well.

Visit www.nhs.uk/livewell for wellness advice for all.

Q&A: Gerard Doran

Gerard Doran in County Armagh, aged 62 with young-onset Alzheimer's.



What's changed most since your diagnosis?

I was diagnosed last October, at the age of 61. My diagnosis was a bit of a shock but receiving that diagnosis has actually helped me. It's helped me understand what I was experiencing, the types of symptoms etc, but it also helped me to develop new strategies to help address some of those difficulties that I was experiencing.

I have a little forgetfulness and some memory problems, but I am still feeling strong and feel that I'm able to cope.

What would you take to your desert island?

My best option would be my mobile phone with my earphones, because music is a massive part of my life, particularly Golden Oldies – 60s and 70s mostly. I'm a major Frank Sinatra fan!

What song or tune sums up your life so far?

I recorded my own song that I wrote to thank a local charity that I joined called Dementia NI, which you can watch on their YouTube

channel. Becoming a Dementia NI member was an opportunity for me to meet somebody else who actually has a similar diagnosis and was already involved. And their friendship and support has helped me to feel that I'm just not alone, not on my own.

What single thing improves your quality of life?

I'm pretty lucky to have very good support from wife, family and friends, but the main priority on my personal level is the programme around my weekly routine that keeps myself occupied. That helps me to establish a feeling of purpose and achievement, positivity, and even physical fitness. And reminiscence is very important in that. Music and singing is a major part of that, hillwalking, meeting my friends and continuing to be involved in the local sporting club.

If you could go back in time, where would you go?

I'd actually go back to work. Work was a massive part of my life – as a youth worker, as a person who looked after families in crisis – and

I'd love to be doing something of that nature. Part of what I always wanted to do was support people and help people.

What is your most treasured possession?

I think it's my house because it's lovely and well situated, close to family and friends, feels very safe and very secure, lovely garden... so I just feel as if this is a big help to me.

If you have dementia and would like to answer our questions for a future column, email magazine@alzheimers.org.uk

Moving forward stronger

Alex Morden Osborne, Public Affairs Officer, on making sure the government provides the support people need to recover from the pandemic's impact.



Back in June, we published *Moving forward stronger*, a paper that calls on the government to introduce a clear strategy to help people with dementia recover from the impact of the pandemic.

People affected by dementia have had an incredibly challenging 18 months, from delays in diagnosis to disruption to their usual support services, including rehabilitation. Many people with dementia have seen their condition deteriorate at a much faster pace than usual.

We want the government to fund a two-year rehabilitation strategy to help ensure people have all the therapeutic support they need. Even while the UK Parliament has been on breaks for summer and party conferences, it's been important for us to continue making noise about this.

Moving forward stronger was written jointly with nine other charities and professional organisations. This consensus makes it all the more likely that politicians will stop and listen to what we have to say.

My next goal as part of this work is to get MPs to agree to hold a debate on Moving forward stronger in Westminster. This will help make sure that our asks stay at the top of the political agenda and gives us the best chance of making our recommendations happen.

A lot of my team's work involves developing relationships with politicians behind the scenes, supporting what they're doing on behalf of people affected by dementia. We can provide briefings and suggested questions, as well as statistics for their local area. These positive relationships provide a good basis for us to ask them for further support.

Thanks to this kind of work, Conservative MPs Paul Bristow and James Davies and Labour MP Barbara Keeley attended our launch event in June. All three have been brilliant advocates for people affected by dementia in parliament and have said they'd support a debate on Moving forward stronger.

Trying to achieve political change is often a long-term project, and one that can feel frustrating at times. Since starting at Alzheimer's Society in March, though, I've been inspired by how much we've been able to achieve for people affected by dementia.

Our #CureTheCareSystem campaign helped make sure that there's more pressure than ever on

the government to bring forward social care reform this year. The time is absolutely right for us to claim some more wins – watch this space!

Help us achieve meaningful change – visit alzheimer.org.uk/campaign to get involved.

Sube Banerjee, Trustee

Why dementia, why the Society?

I was convinced I was going to be a child psychiatrist until, a year into my training, I started working with older people with mental health problems and people with dementia. I was so taken by the amazing stories they had, and by how much could be done to help by services but which was not being done.

More recently, my father had vascular dementia and my grandmother had Alzheimer's. Supporting my mother as she looked after them reinforced my commitment to improving care, and the Society is at the forefront of making dementia a priority.

How to fill an unexpected day off?

I'd like to stay in bed, but my dog Stanley wouldn't let me! So it would first be a walk by the sea on the Rame Peninsula – a beautiful corner of Cornwall just across from Plymouth, where I work.

Then I would jump on my carbon-neutral magic carpet, with Stanley, which would take me back to London and I'd go to the National Theatre with my wife. The play would be great and that would be a perfect evening.

Proudest achievement?

Seeing my children grow up to be such great people (nothing to do with me, everything to do with my wife).

My oldest son, Manny, is 26 and he is autistic and has learning disabilities. He's just finished a film course and produced a brilliant documentary on the 'superpowers' of people with disabilities.



My younger son, Jasper, has been at university all over the pandemic and has, despite the adversity, produced some absolutely beautiful pieces of work, again in film.

Worst advice you've been given?

A very senior academic said it was vital for me to focus only on research – I shouldn't spend time developing services and I certainly shouldn't prioritise clinical work. I nodded and said I was extremely grateful for the advice, which I had already disregarded as I left his rather grand office.

Complex problems need multifaceted responses and I knew that I needed to innovate, deliver and lead services, as well as evaluate them, so we could get to a better place.

Biggest priority for coming months?

To help the Society make the case that dementia needs to get right

back as the top health and care priority. In the 18 months of the pandemic, policy and priority for people with dementia has gone back what seems like 18 years. Our job is to win back those 18 years of progress over the next 18 weeks.

Most important thing learned from a person with dementia?

From all people with dementia, that a person with dementia has all the same desires, needs, wants and interests, the same aspirations, sadnesses, glories and successes as any other person. People with dementia are people first and foremost – dementia doesn't make you any less of a person.

Most looking forward to?

To things being different. To society rediscovering that we need to be able to do more than one thing at once and not focusing solely on COVID. To developing a different approach to health and social care, that respects and values older people and their life quality.

I'm also looking forward to spending a lot less time on Zoom and more time with humans!

‘Take her name and say it’

The winners of our poetry competition 2021.

We were humbled by the massive response to our 2021 poetry competition – 141 of you sent us 220 poems, more than ever before. Thanks to every one of you for taking part, as well as to the amazing shortlisting panel and our guest judge, award-winning poet Vahni Capildeo.

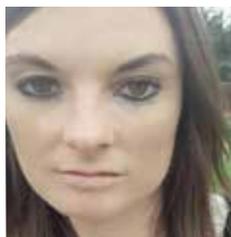
Panel members included Pete Middleton in Northamptonshire and Gail Gregory in Lancashire, both living with dementia, along with Zaki Shah in London whose mother writes poetry and has dementia, and the poet and playwright Maria Jastrzębska in East Sussex whose parents both had dementia. They were joined by two of our 2019 competition winners – Miranda Overett, now in Budapest, and Damon Young in Berkshire – and Helen Helmer, who heads our Publishing team.

Pete was keen to recognise all who entered, saying, ‘I would love to get everyone into a hall so we can give them a huge round of applause.’

Vahni adds, ‘The poetry which you generously shared for this competition shows real care for the musicality of language and the craft of words.’

‘I mean it from both head and heart when I say that you poets are all winners, and that I hope you continue writing. You are writing about aspects of life that need to be heard, in ways that reward a hearing.’

Category: From the heart



These were poems judged to authentically express a person’s experiences of their own or someone else’s dementia. First place went to ‘The faces of sickness’ by Sian Breeze in Gloucestershire, a poem that Vahni described as ‘a beautiful achievement’.

‘Told in language that looks unadorned, this poem gently holds itself together with simple echoes (“sick”, “back”, “batter”, “butter”),’ says Vahni. ‘Its art consists in allowing breathing space to images that have a slow but extraordinarily profound impact.’

‘The insistent focus on celebration, on the presence of three generations, and the youngest learning that “sick” can look “good”, is a courageous challenge to stereotypes of illness meaning unmixed misery and fear. The fact that the young son is surprised shows that those stereotypes hold some truth.’

‘Hope and gratitude are decisions, not just passing feelings. This poem has the sweet toughness to foreground that lesser-heard, much-lived truth.’

Sian says, ‘I am training as a mental health nurse right now, so have had the privilege of working with lots of different people with the condition.’

‘This poem was written about my father-in-law, who had Alzheimer’s and passed away this January after a fall. My son, like many children, found the illness confusing. He couldn’t understand how Grandpa could be short-tempered and solitary one minute, unable to be around his grandchildren, and how he could laugh and be very jovial at other times. This poem is about the complexity of being unwell, and tries to focus on some of the positive times we had.’

The faces of sickness

We told our son
that Grandpa’s brain was sick.
As we watched you flashing your row of white teeth,
 leaning your head back,
your thin mouth opening like an entrance to another world.
You swallowed us up with your laughter,
your happy tears fell like cake batter from a spoon.
We watched you at the table
supping ale that tasted like soft butter,
as our son stared on at you
and wondered to himself,
 how sick could suddenly look so good.

© Sian Breeze



Second place went to ‘Day 5 Bath’ by Valerie Bence in Buckinghamshire, which intrigued Vahni by its title.

‘This poem conveys the extreme peril that “ordinary life” like bath time has for those of us who are frail,’ says Vahni.

‘The mother is literally on the edge – at the edge of the bathtub, but also poised between life and death. She grimly warns her daughter not to live as long as she herself has.

‘However, despite this grimness, the quality of attention in the poem gives an overall impression of tenderness. Crafting the language to tell us this story is an act of tenderness which is just as true as the refusal to look away from the pain.’

Valerie says, ‘In 2019 I took over the main care for my mum from my brother for a month while he went on a long-awaited trip to see his new grandson in Australia. I was both daunted and unprepared for the reality of the responsibility. The month became a 30-day poetic diary – and this was indeed Day 5.

‘Subsequently, Mum had a fall, hip surgery, her dementia rapidly deteriorated and she died about six weeks after being transferred to a care home. Just pre-COVID, it was a traumatic time and her last few weeks will stay with us. However, to have part of this diary chosen in this way has been wonderful.’

Day 5 Bath

Bathroom as hot as a sauna

clean clothes found

bath run. I tested the temperature as for my babies,
later

she called for help getting out –

but with her voice as weak as a
pipit’s

and my hearing half-disappeared, I didn’t
hear her straight away, just a minute or two
but when I went in

her tiny frame perched on the bath edge
exhausted by the effort of trying to become vertical
with knees that won’t bend;

so, I lifted her

lifted my mother, towel-wrapped

thin arms around my shoulders, from the bubbles
shaking with pain no longer hidden –

oh she said this is awful, don’t get this old lovie

and this double-edged benison

gave me the truth of that.

No don’t.

© Valerie Bence

When’s she coming?

9.25am He arrives. “See you later, love.”

9.35am The well-dressed gentleman
Sitting silently, anxiously by the window.
“When’s she coming?”

A question asked again and again.
“When’s she coming?”

Holding his hand

Offering tea and cake

Distracting with talk of the weather

“When’s she coming?”

10.30am Staying close-by

Stepping back with him

Into his past

Going with him, letting him lead the way

Trying to grasp his reality.

11.45am “Come and have lunch.”

“When’s she coming?”

Sandwich untouched

Hands worrying at the edge of the coat he
refuses to take off

“When’s she coming?”

2pm

A game of Snakes and Ladders

He slips back and forth

Now today, now ‘before’

And back again

“When’s she coming?”

His mind manoeuvres like the counter

Laboriously up the ladder to ‘before’

And a lurching drop down the snake

Back to ‘now’

“When’s she coming?”

3.30pm A car

An elderly lady

His face lights up

His sweetheart

The question finally laid to rest –

For today

© Sue McFeely

Third place went to ‘When’s she coming?’ by Sue McFeely in Gloucestershire, which Vahni called ‘a dramatic poem’. ‘It is a drama of waiting,’ says Vahni. ‘Waiting is a huge part of life: whether in



traffic, in a post office queue, on the hospital ward, behind the lines in war, or just for a mobile phone to charge. Waiting becomes intensified to high drama in environments such as care homes.

‘This poem is not about being a “patient”, or about having patience. It is about the yearning that characterises the lover in the beloved’s absence. It gives the dignity of the long tradition of the love poem to a person in the autumn of their life. It’s impossible not to be moved.’

Sue says, ‘I was inspired by witnessing the sadness and anxiety of an elderly gentleman who came to the Tewkesbury Day Centre for a few weeks so that his wife could have a break. As soon as his wife drove off, he would start fretting and asking what time she would be back. The relief when she returned was written all over his face and his eyes would light up with absolute joy.’

‘It’s amazing to be chosen as a winner; it was so moving to see his two extremes of emotion and I’m really happy to have the chance to share this.’

Other poems shortlisted in ‘From the heart’ were ‘Funny How’ by Yvie Holder in East Yorkshire, ‘Reminiscence group’ by Sue Ibrahim in Kent, ‘Memories’ by Sarah J Bryson in Oxfordshire, ‘Afterwards’ by Pat Harland in Nottinghamshire, ‘Music and Silence’ by Jennifer Willis in Norfolk, and ‘Mum Says Ooh’ by Steven Croft in Greater Manchester.

Category: A way with words



These were poems using techniques such as rhythm, form and imagery to move us or make us think. First place went to ‘Against Intruders’ by Ruth Higgins in Hertfordshire, which Vahni described as ‘a brilliantly tender and

minimal charm against the inevitabilities of decay’.

‘It is a poem strong enough to conjure a “fear not” while being humanly true to the terror we feel as our selves are lost to ourselves,’ says Vahni.

‘This poem, arranged in couplets, begins with “And”, placing us in the middle of some process already begun. It is, cleverly, a countdown poem. There are three appeals, or reminders, to “Take”, “take”, “take” steps to remember things in words. Then there is a twice-repeated action of drawing. These and many more subtle and overt techniques chart what is happening to the human person, without losing the musical, almost magical, qualities of language.’

Ruth wrote ‘Against Intruders’ for a close friend who has Parkinson’s disease with dementia.

She says, ‘When I wrote this poem, I was thinking of those times when we draw on significant moments and everyday positive experiences to “hold our ground” when things get difficult.’

‘I was amazed to win and really delighted that the poem spoke to a writer as brilliant and inventive as Vahni Capildeo.’

Against Intruders

**And when they come unwelcome to your garden,
when your garden doesn’t know you anymore,**

**take the five notes a blackbird sang last evening;
take 1986 and write it down in tiny figures**

**on white paper. Take her name and say it;
add *My wife*.**

**Draw a cube in pencil, a perfect cube:
the best they’ve ever seen. Do it again.**

**A mug of tea on the pine table: feel it
between your palms, steady and warm.**

© Ruth Higgins



Second place went to ‘The Bloodknot’ by Peter Russell in Glasgow, which Vahni thought was ‘a powerful poem’.

‘The great technical control of the consistent image of fishing, drawn from lived

experience and extended into symbolic meaning, is matched by the skilful use of the tercet form and of rhymes, near-rhymes, or off-rhymes,’ says Vahni.

‘This control is counterpointed by surging emotions just below the surface. There is new depth to this disturbing, beautiful work on every re-reading.’

‘I especially loved the run-on lines in the last two stanzas and the double meaning of “reel in memories”, which felt at once accelerated and elegiac, like the progress of loss even while the moment is cherished.’

Peter says, ‘My father had a prodigious memory, including for the things that he picked up and were useful for fishing. I noticed that he was losing interest in fishing as he became affected by his dementia. This of course saddened me greatly, both on his behalf and because it was something that we shared, both when I was a child and in later life. I always remember him for sharing it with me – and I will always be grateful.’

'I am of course honoured. I also read the poem to younger people at spoken word events, hoping they will get an insight into dementia and the losses it brings.'

The Bloodknot Dedicated to Reg Russell, 1929–2021

Before I could hold a rod, I would help watch your float—
A permitted treat when I enjoyed the stillness of
fishing with you,
And marvelled at how you waited so quiet and caught

Red-eyed tench, furtive carp and stripey perch from
coarse water
Rivers and ponds; and as mates when I could fish too,
On the grey Solent in an orange dinghy with a two-
stroke motor

Trolling feathers for mackerel, or float fishing for
bream on the tide
Waiting as patient as you were with me for a bite;
You knew sandbanks, and marks, and wrecks that
would hide

Mythical monster conger eels, or shoals of flatties in
the mud
You knew how much bait and just how much weight
To keep the float upright and hold bottom on the sea
bed

So let's get the rods out again: use our bloodknot of
lines and skills
Before the tide sinks your memory among the wrecks
We'll ledger for names tugging in the deep, cast lures
for words like eels

And together we'll find the right bait and the hooks and
lines to match:
Still mates, me waiting for your float to vanish, and you
to strike
And reel in memories, glinting from ever deeper, and
ever harder to catch.

© Peter Russell



Third place went to 'Salad' by Sadie Maskery in East Lothian, described by Vahni as 'a deceptively artless poem'.

'Every sound has been chosen with absolute care, from the rough, potentially conflictive r-, sl-, fr- and st- sounds of the

beginning to the softer l- and sl- sounds which overtake the poem's soundscape,' says Vahni.

'The act of making something ordinary, nourishing, and everyday – a sandwich – and how that act, from being simple, turns into a challenge, is potently symbolic as well as true to life, an excellent image for the condition under consideration. The unexpected "harder he cried", rather than the more expected "harder he tried", delivers a shock of deep pathos as a strong man loses his grip. Wonderful work.'

Sadie says, 'It is a privilege to be part of something that helps to spread awareness of Alzheimer's and the different ways it can affect people living with it as well as those around them. Thank you for the opportunity.'

Salad

We learned to roll with his anger,
frustration as our respect
slipped from his grasp
the harder he tried.
One day, "Dad", I said,
"The fridge door."
He turned and roared at me
"NO. I meant that, I need it open,
I have not finished yet.
You are stupid.
You are stupid, not me.
Stupid woman.
I need it.
Open."
For the next hour it gaped,
the light burning, lettuce
softened by the summer sun.
"All right? That's how I like it.
I like it. Open."
The fear behind his eyes
as he made us sandwiches
with wilted leaves, butter that
slipped from his knife
the harder he cried.

© Sadie Maskery

Other poems shortlisted in 'A way with words' were 'Fleeting Memories' by Taymaz Valley in Cambridgeshire, 'A Clean Break' by Fiona Heatlie in Glasgow, 'A kaleidoscope of memories' by Gary Hodge in Devon, 'The last goodbye' by Margot Tilbury in Hampshire, 'That Old Dance' by Catherine Charwood in Liverpool, 'Pushing your dotage' by Anna Somerset in Greater London, and 'Looking Games' by Amanda de Blaquièrre in Wirral.

You can share your poems about dementia in the members' area of our online community, Talking Point – visit alzheimers.org.uk/talkingpoint

In your area



Moy Park milestone

Northern Ireland's largest private sector business celebrated raising almost £25,000 for Alzheimer's Society in six months.

Moy Park, which produces poultry and other food products, launched its charity partnership with us in March. Since then, its team members have been raising awareness of dementia while also fundraising. Activities have included Zoom quizzes, a sponsored 24-hour 'walk around the clock' and a virtual trek across America.

Kirsty Wilkins, the company's HR and Performance Director, said, 'We are proud to be working with Alzheimer's Society to raise awareness of dementia in the communities where we live and operate.'

'Dementia affects hundreds of thousands of families across the UK, and Alzheimer's Society is working tirelessly to find a cure while also supporting people and helping them to live well and stay connected.'

Jenay McCartan, Community Fundraiser at the Society, said, 'We are absolutely delighted that our partnership with Moy Park has got off to such a great start.'

'The pandemic has been devastating for families affected by dementia and they need us now more than ever. This money will help us reach and support more people through our vital services.'



Photograph: Brian Williams

Matthew Walks Wales

A musician from Penygraig in south Wales has raised over £2,300 for the Society by walking the entire 1,400km Wales Coast Path over 66 days.

Matthew Frederick, frontman of Pontypridd band Climbing Trees, arrived in Chepstow on 5 August after setting off from Chester on 1 June.

As a full-time musician, Matthew was facing a summer with none of the usual gigs thanks to the pandemic. He decided to use the opportunity to take on a challenge he'd wanted to do for years but hadn't had the chance to.

Caysha, Matthew's wife, set up a JustGiving page called Matthew Walks Wales to deal with donations as they came rolling in, helped by coverage in local press, radio and online news sites.

She said, 'It was a very easy decision to support Alzheimer's Society, and for those of you who have personally been affected by it, you know how utterly cruel and heartbreaking this disease is.'

Matthew added, 'A massive thank you to family, friends, fans and anonymous money-givers, as well as the occasional cash-in-hand donation from generous strangers along the way.'



What a wonderful world

A Gloucestershire duo is raising funds through a charity album called What a Wonderful World, two years after a chance encounter led to them recording together.

When Maurice Craft bought a car from Stacey Thornhill, they got chatting about the passion for performing they shared despite a 50-year age gap.

Maurice had decided to create an album to honour his wife Dorothy (pictured), who was diagnosed with Alzheimer's six years ago.

'A few weeks after our chat, Maurice came back to the showroom and said he had decided to have a female voice on the album as well as his own,' says Stacey, who lives in Lydney.

Maurice, from Alvington, says, 'It was seeing my lovely wife fighting this terrible disease that inspired the project. I thought I must do something not only to help Dorothy, but all the lovely people out there who may get it as well.'

The album's songs were carefully chosen to tell the story of Maurice's relationship with Dorothy, a former competitive ballroom dancer. What A Wonderful World, by Maurice & Stacey, is available on Apple Music, Amazon Music and Spotify, with all profits from its sale going to the Society.

Passion to educate

Tracey Seymour wants to challenge the perception that dementia only affects older people. **Gareth Bracken** speaks to a carer whose husband was diagnosed in his mid-50s.

Quick read

Tracey Seymour in Somerset is raising awareness about the impact of dementia on younger people.

Tracey's husband Paul was diagnosed with young-onset Alzheimer's in 2014, aged just 54, after experiencing memory problems.

Paul, a printer turned construction labourer, continued working for years after his diagnosis with a supportive employer.

Tracey and Paul are urging people in their 50s who have memory problems to get it checked out.



Since her husband Paul was diagnosed with Alzheimer's aged just 54, Tracey Seymour has been on a mission to raise awareness about the impact of dementia on younger people.

'So many people think this is part of getting older but it's a disease, like cancer, not a normal part of ageing,' says Tracey, who gave up work to care for Paul.

'Paul was in his 50s with a job and a mortgage. I want to shout from the rooftops that dementia is not just about granny and grandad.'

Shock and denial

Tracey and Paul live in his hometown of Midsomer Norton in Somerset. They married within 15 months of meeting and recently celebrated their 39th wedding anniversary.

Tracey is a trained hairdresser who more recently worked as a private cleaner. Paul, now 61, worked as a lithographic printer before redundancy led to him becoming a construction labourer. They have two children and three granddaughters.

Tracey recalls the first signs that something wasn't right with Paul's memory.

'He used to come home and say that the younger lads were playing jokes on him, moving his tools and kit,' she says.

'There's a level of forgetfulness that you know you shouldn't really have, when you frequently forget dates, times and names. That's

when Paul said to me, "There's something going on."

Paul saw his GP, and tests at a memory clinic suggested he might have mild cognitive impairment, where someone has minor problems with mental abilities such as memory or thinking. Further tests and two brain scans later, Paul was diagnosed with young-onset Alzheimer's in October 2014.

'Paul just said something like, "Okey-dokey,"' recalls Tracey. 'I think he was shocked and in denial. I felt relief – "Now we know what we're dealing with."'

On a quest

Tracey noticed that the posters and leaflets at the memory clinic only showed older people, which motivated her and Paul to challenge that perception by sharing their story in the media.

'We went on a campaign to raise awareness that dementia can happen in under-60s,' she says. 'We did daytime TV, that was very exciting. You go on a bit of a quest and get very wrapped up in it all.'

The couple also did two successful Memory Walks in Bristol and Bath, to raise vital funds for Alzheimer's Society.

Sad and frustrated

Tracey and Paul tried to carry on as normally as possible, including continuing to work. However, the progression of Paul's dementia has been very noticeable.

'Alzheimer's is not just memory loss, but also your whole thinking

process,' says Tracey. 'On a bad day, he'll struggle to make a cup of tea and will ask me for help. Dementia affects every single task he does.'

Tracey, who has lasting power of attorney for Paul, says that her husband's abilities have declined more quickly than she ever expected.

'Paul is a fun-loving, bouncy, bubbly person, but forgetting people's names or not getting a sentence out makes him sad and frustrated,' she says. 'It's the whole sadness of it all. He's only 61.'

Amazing employer

Paul worked for a property developer for five years, until March 2020.

'Paul's employer was amazing,' says Tracey. 'He employed Paul after his diagnosis. I expect a lot of people wouldn't do that, so we were very grateful.'

Paul's duties at work were changed as time went on, to allow him to remain in the job for as long

as possible. His last day was in early March, just before the pandemic took hold.

'He was distraught to lose his job and then it was lockdown – it was a double blow,' says Tracey. 'That's where I saw the biggest change, in those following months. It all had a big impact on Paul.'

With Paul's dementia seeming to progress particularly quickly during late 2020 and early 2021, Tracey decided to give up work.

'I wanted to be here with Paul all the time, so in January I decided not to go back,' she says.

'First and foremost I'm Paul's wife, but I'm also now his paid carer, because of Carer's allowance. I see it as my wifely role and as my job.'

Tracey is making adjustments 'all the time' at home.

'I might have to reword something in simpler language or, if I want to involve Paul in mowing the lawn, he'll go beside me, holding the wire,' she says.

Community comfort

Tracey and Paul receive excellent support from family and great understanding from friends. Tracey has also found Talking Point, the Society's online community, extremely useful.

'For three years at the beginning, that was my go-to. I was on there all the time, spouting off!' she says. 'Although I couldn't see them, people understood and were in the same boat as me. It was my comfort, they knew exactly what I was feeling and saying.'

Talking Point members gave Tracey the idea of printing and keeping lots of photos from holidays and occasions, for Paul to look through. The couple are also keen runners, regularly joining their local Parkrun.

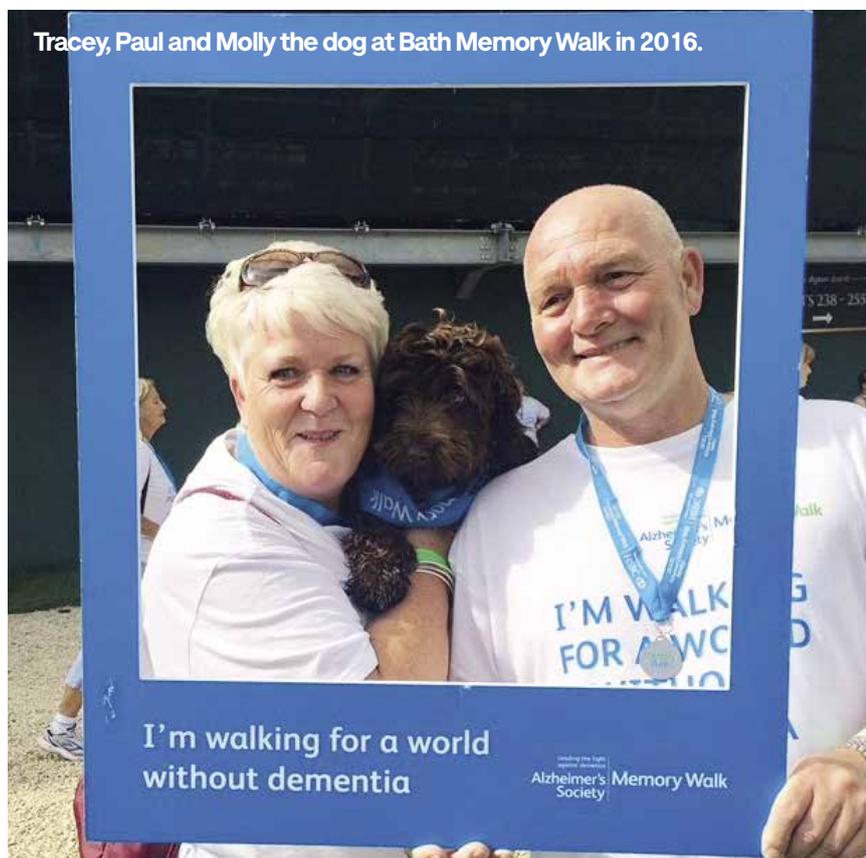
'They all know Paul has Alzheimer's, so the marshals help him with the route if he gets a bit muddled,' says Tracey. 'I want to keep Paul fit and healthy, and look after my own wellbeing.'

Tracey is also now supporting her 89-year old mum, who was recently diagnosed with Alzheimer's.

'I have bad days and sad days, but I'm a great copper and I feel quite strong,' says Tracey.

'I borrowed a famous phrase when I said that there's three people in our marriage – me, Paul and Alzheimer's. Paul's retirement has been taken away and we've had to reroute our futures.

'I know what the future entails, but you can't change it, so you just have to make the most of what you've got and live in the here and now.'



Visit alzheimers.org.uk/talkingpoint to join our online community.

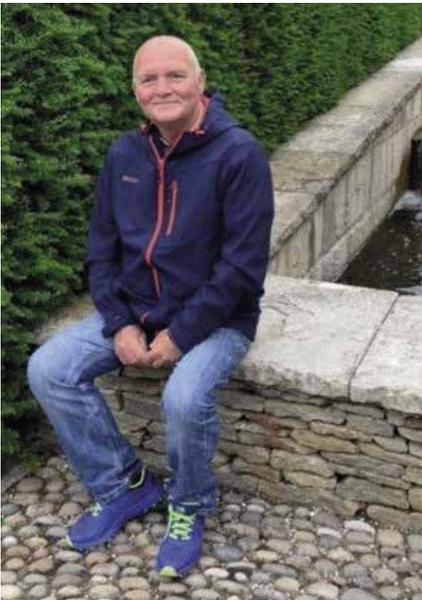
Get checked

For Tracey, the here and now includes spreading the message that dementia can affect younger people.

'It's my passion to try and educate people about it,' she says.

'Men of Paul's age don't always talk about things, but if you're 50 and have a bad memory, go and get it checked out. Paul always used to say that he'd want other people to do that.

'If we help even one person to go to the doctor about their memory, we've done our job.'



Tracey and Paul at their first Memory Walk, in Bristol in 2015.



For our Young-onset dementia: Understanding your diagnosis (688) factsheet, visit [alzheimers.org.uk/publications](https://www.alzheimers.org.uk/publications) or call 0300 303 5933.

Donate

You can support people affected by young-onset dementia come to terms with a diagnosis. **Donate now.**



Open again

After its forced closure last year, our Dementia Resource Centre in Peterborough is back with some new-look services. **Gareth Bracken** finds out more about this much-missed source of support.

Quick read

People affected by dementia are once again receiving face-to-face support at our Dementia Resource Centre in Peterborough.

The popular hub was forced to close during the pandemic but has reopened to host groups, with some now delivered by local organisations.

Christine, who has vascular dementia, is delighted that she can again meet and chat with different people at the centre.

The centre is also back hosting our Carer Information and Support Programme (CrISP), which carer Louise Yates found extremely helpful.



Our Dementia Resource Centre in Peterborough is a popular hub that acts as a one-stop shop for people affected by dementia who need advice, information and support.

Its specialist services, including face-to-face groups, have served the local community since 2014, providing the help and guidance people need to enjoy a good quality of life and live as independently as possible.

Like so much else, the centre's activities were severely disrupted by the pandemic, with support forced to move online or over the phone. Thankfully face-to-face services have recently returned, with many different to before.

New partnerships

Previously, Society staff ran various face-to-face groups at the centre. They continue to deliver Singing for the Brain, peer support and educational programmes. Our new contract to run the centre began in April, and with it came changes to how some of the other groups are delivered.

'We are bringing in other organisations and partners to run a variety of activity groups,' says Siobhan Merrygold, Dementia Connect Local Service Manager.

'This will give people affected by dementia access to more resources and frees up our time to reach the people who most need our specialist support.'

Our support service in the area has returned to face-to-

face appointments, alongside continued phone support.

One of our key partners is City College Peterborough, whose students now run the centre's dementia café, as well as offering a hairdressing service. These services often relate to what the students, aged 16–24, are studying or the field in which they want to work.

'These opportunities are an excellent way for our college to give back to the community, bring a smile to people's faces and support our young adults – some of whom have a learning disability – to grow their independence and transferrable skills,' says Sally Elsom, Business Development and Careers Lead at the college.

Tasha Dalton, Vice Principal at the college, says that students and adults with learning disabilities will deliver a high-quality service for people affected by dementia.

'We want to provide a café that recognises and supports people's individual needs,' she says. 'We are proud to be working with the centre, creating a safe, calm and inclusive space.'

Use our Dementia Directory to find dementia services near you – see [alzheimers.org.uk/dementiadirectory](https://www.alzheimers.org.uk/dementiadirectory)

Not the same

Christine, who has vascular dementia, was one of the first people to return to groups at the centre in September. She loved attending before the pandemic.

'I really enjoyed it. The people made you feel welcome and were very helpful. It was a good laugh,' she says. 'When it all stopped – oh no! We went onto Zoom. It's OK, but not the same.'

Christine previously attended a peer support group called Open Minds, now called Think and Share.

'If you've got any problems, you can talk to them, they don't go and tell anybody else. It's private and confidential in the building,' she says.

Under the centre's new contract, a local theatre is also hosting Singing for the Brain, which Christine has already been to. She's delighted that the place has reopened.

'I think it's great!' she says. 'I can't be stuck in. I want to meet different people and have a nice chat.'

Still here

Society staff were able to offer in-person appointments at the centre as of June, while July saw the face-to-face return of the Carer Information and Support Programme (CrISP).

Louise Yates is a carer for her 72-year old mum Marion, who was diagnosed as having dementia with Lewy bodies in April 2020.

'It's hard to put into words just how much attending CrISP at the centre helped me,' she says. 'The programme improved my knowledge, gave me helpful ideas and outlined the practical help available, all delivered by experienced and understanding staff.'

'To me, dementia often feels like the "dementors" from Harry Potter, sucking the life and happiness not just from the person but also their family members. I had been feeling quite isolated and lonely after giving up my job to care for Mum full time, so being able to finally meet the staff and put faces to names was invaluable.'

'The centre staff and the people who access it already feel like a family to me. They have been a real lifeline and have helped me to realise that I don't have to go it alone. We carers have already swapped details and are going to meet up again at the centre soon.'

Siobhan is thrilled that the Dementia Resource Centre is once again delivering vital face-to-face services for people affected by dementia.

'It's been a challenging time for us all, and while on the surface we appear to be returning to normal, we know that things are far from normal for many people,' she says. 'We want to get the message out that we are still here for support.'



Marion and Louise.



Tasha.



Talking Point, our helpful online community, is free and open day or night – find out more at alzheimers.org.uk/talkingpoint

Donate

You can ensure that vital support is there for more people affected by dementia. **Donate now.**

A friend at home

People with dementia are benefiting from sharing their home in return for support and friendship. **Gareth Bracken** reports on the benefits of homeshare.

For people who need some support to live independently at home, homeshare is an approach that can match them with someone who's happy to provide practical help and friendship in return for affordable accommodation.

Share and Care Homeshare is a community interest company that's matched hundreds of homeshare arrangements over the past 15 years, including with people who have dementia.

The householder provides free accommodation to their 'sharer' in exchange for 15 hours of help and company per week. Both parties pay a small monthly fee to Share and Care Homeshare to match, monitor and mentor each arrangement.

Genuine friendships

Share and Care Homeshare was founded by Caroline Cooke, whose late father had vascular dementia. Caroline is a Dementia Friends Champion who runs information sessions for family members and sharers.

She runs Share and Care Homeshare across the UK alongside director Amanda Clarke.

'We call ourselves professional matchmakers,' says Amanda. 'You have an image in your head of what someone is looking for and what someone else can offer.'

The company will consider an applicant's hobbies, interests and availability.

'We're looking for genuine friendships to develop, so you've got to go deeper and find out if they have things in common. We ask people a lot about their lives,' says Amanda.

'We also do all of the required checks and ask for sensible referees. Homeshare works because we take the matching very seriously.'

So, what makes a good sharer?

'We're looking for empathetic people, perhaps who have done volunteering and have some understanding of older people,' says Amanda.

'We want people who are happy to give their time – it shouldn't feel like a job or be treated like a job.'

'A great match is where both sides understand that there needs to be a balance.'

Amanda is keen to make more people aware of homeshare as an option.

'With future social care reform, homeshare should be more firmly on the agenda,' she says.

Quick read

Some people with dementia are sharing their home in return for practical help and friendship through homeshare.

Share and Care Homeshare match and monitor homeshare arrangements, including with people who have dementia.

Katie Barr-Sim is full of praise for the homeshare arrangement between her mum Flo, who has memory problems, and 'sharer' Luciana Canu.

Luciana describes Flo as a friend, and Flo says Luciana has become like family to her.



Caroline Cooke and Amanda Clarke



Keep an eye

In south-west London, Flo and Luciana have been matched in a homeshare arrangement that's been a success for both of them.

Share and Care Homeshare were approached by Flo's daughter, Katie Barr-Sim. Katie lives three hours away from Flo, who has memory problems, and became aware her mother wasn't always taking her medication.

'It was evident that Mum needed more support, so I looked at the whole gamut including care agencies and care homes, but a friend suggested homeshare, which we started 18 months ago,' says Katie.

'It's perfect for the stage we're at, as Mum is not yet ready for full-on care but is still enormously worried by her loss of memory.'

The arrangement has been working very well for all involved, with Flo able to stay in the home she's lived in for 40 years.

'My dad died three years ago, so homeshare animates Mum's house and connects her with someone younger,' says Katie.

'Luciana can nudge Mum into her routine and trigger reminders for her to take her medicine, or that she's seeing a friend that day.'

'We try to visit every 10 days, but Luciana helps me keep an eye on things without being too invasive. I can ring up and say, "Has the letter come from the doctor? Have the gas people been?" It protects Mum's dignity in a way.'

Katie says that Luciana was a great help to Flo during lockdown.

'Mum hasn't really got the intellectual capacity to entertain herself, but Luciana is jolly and upbeat, and they have great fun. Luciana's humanity is exceptional and she has really added to Mum's life.'

Like family

Luciana Canu, who is from Italy, has benefited from the arrangement as well.

'I really want to study graphic design, which is very expensive, and with homeshare I can save some money with low-cost accommodation and possibly change my career in future,' she says.

'But it's more than just material – I can also improve my English and fulfil my dream of experiencing this culture.'

Luciana has developed a close relationship with Flo.

'Flo is like a friend, we often go out together for a walk or to have a coffee. She'll come out with me and my friends,' says Luciana, who also felt very supported by Flo's family during the pandemic.

'The activity she enjoys most is picking up litter at the park, because while we are looking after the environment, she can also chat to curious people who approach us.'

'We are basically two women of different ages who met at the right time and in a particular moment of our lives, so we help and support each other.'

Most importantly of all, what does Flo herself think of all this?

Smiling, she tells Katie, 'Well, Luciana – she's just become like family now, hasn't she?'

Use our Dementia Directory to find dementia services near you – see alzheimer.org.uk/dementiadirectory

Find out more about Dementia Friends at dementiafriends.org.uk

For more about Share and Care Homeshare visit www.shareandcare.co.uk or call 020 3865 3398.

Consumer panel

Our panel tries out players for radio and music that have been designed to be easier for people with dementia to use.

Music and radio



This issue, we return to our West Sussex consumer panel of people affected by dementia. They tried out some new and existing radios and music players at home, and we caught up over Zoom to see how they'd fared with them.

Two of the products were from Ravencourt – one existing player plus the prototype of another that's in its final stages of development. The third was a new radio and music player from Relish.

One Button Radio

The One Button Radio has long been a success with people who want to use a retro-looking AM/FM radio without having to deal with lots of dials and buttons. After setting the station and volume, and covering these controls with the panel, you can then turn the radio on and off using the single button on top.

Although Bob and Jane found getting the panel off their radio a bit fiddly, setting it up after that was straightforward (and Oli from Ravencourt said the particular issue with their panel had since been fixed).

'It was very easy to set up, easy to tune,' said Jane. 'Bob managed to switch it off without even looking for the on/off switch.' Bob thought it looked a bit old-fashioned, but Jane noted that that was the idea, 'It's retro, and that's quite popular!'

Jane said, 'The sound was very good – we were impressed, considering it's not a digital radio. And it's very sturdy, it's very, very difficult to knock over, which is a plus. All round a very good radio.'

They thought the price was fair, and Jane added, 'My father had macular disease, and we had dreadful trouble with him and the radio. This would have been wonderful for him.'

Easy Music Player

The Easy Music Player is based on a similar idea to the One Button Radio, but has a DAB radio and a bright, contemporary look. An initial white prototype was reviewed by our panel earlier this year, but this time we saw a yellow version – a colour chosen by people through the Society's Dementia Voice programme.

John and Joyce said the points raised when the panel looked at the previous prototype had all been addressed, including having much clearer instructions.

While they weren't able to get a radio signal – probably just a problem with this specific prototype – they did play music from a mobile phone using Bluetooth.

'That worked well,' said Joyce, 'though the sound quality on the headphones was better than the radio on its own.'

They also successfully tested playing music from a USB stick during our Zoom session.

John said, 'Even the cover that you pull down to get to the buttons, that was easy to do.'

Joyce was worried about the battery draining, since the button on top only mutes the player rather than turning it off fully. However, Oli said Ravencourt will look into changing this while making other final tweaks to the design.

'We like the concept of a one-press button,' said Joyce. 'We like the yellow as well, it stands out.'

Relish Radio and Music Player

The Relish Radio and Music Player also has simple controls on its top – on and off buttons, a volume dial and four buttons to choose from three radio stations (with labels you can personalise) and a playlist. These options are set using more detailed controls that are then covered by a panel at the back.

Chris said, 'It was really good for Mick. Since we've received it, he has played it every day – and we've got lots of things, like Alexa, that he does not use, so he really likes this.'

Chris said they both liked the packaging and instructions, and had no problems setting up or using it.

'It's not overcomplicated for him, though he's now having trouble doing things like that. The price might have put us off, but because I know that Mick uses it, I would pay that.'

Gordon and Alison also enjoyed this player, saying that it looks 'robust and classic'.

'Part of the appeal is that it looks like a radio we had when I was a young boy,' said Gordon.

Alison added, 'We were very, very keen. I was terrified about setting the programs but that was no problem – I was practically doing cartwheels round the garden after doing that!'

Both couples thought a longer cable would be useful, which Geoff from Relish said was helpful feedback.

Roger also thought it was excellent. 'Once it's set up, certainly from the listener's point of view, just pressing the button and getting music is so much simpler.'

He had already created a playlist for his wife Elizabeth, who's living in a care home, and is looking forward to her being able to hear it on this player.

The One Button radio is £49.99 plus VAT and the Relish Radio and Music Player £83.33 plus VAT, both from our online shop. The Easy Music Player is expected to be available early next year – in either white or yellow – at £79.99 plus VAT.

Visit shop.alzheimers.org.uk or call **0300 124 0900** for products to help people affected by dementia to live well at home. For some products, you don't have to pay VAT if they're for use by a person with dementia or other condition – tick the box stating that you're eligible for VAT relief at checkout.



Mick using his Relish Radio and Music Player.



Win a music player
See p39 for a chance to win a Relish
Radio and Music Player.



We read a memoir from a journalist about caring for his mother after she was diagnosed with Parkinson's disease dementia.

Love and care

A former journalist, Shaun Deeney knows the value of telling real-life stories. Perhaps it's no surprise that, after his life changed unexpectedly, he's been sharing his experiences through a podcast and now in a book too.

Caroline Branney, who manages our Dementia Knowledge Centre, says, 'Love and Care is a lovely, humorous, heartfelt, no-holds-barred story. We follow Shaun as he makes some big decisions about his life following a period of uncertainty.'

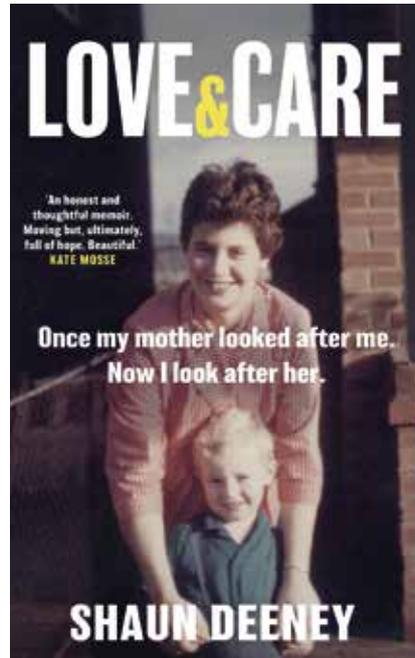
Maggie Woodhouse, a reader in Suffolk, says, 'This is a memoir written by a son who shifts his life to care for his mum in her home. It is written over a year in which both he and she go through some momentous changes.'

Shaun's mother has Parkinson's disease dementia, and Caroline says, 'He feels that, once his father has died, he owes it to his mother to retrieve her from her care home and support her in her own home, since he is divorced and has few other commitments.'

John Spriggs-Taylor, in Derbyshire, says, 'I think we should all be eternally grateful to Shaun. Like many late middle-aged men, I find myself in a similar situation. A former this and a former that, I have been a full-time carer for my mum for some years. I wish I'd had Shaun's book when I set out on this adventure.'

One of a kind

Myrtle Stephenson, a reader in Nottinghamshire, says, 'I found Love



and Care very easy reading, not what I expected of a book relating to dementia. The author really seems one of a kind.

'The book is interesting as it does not relate just to his mother but his own life story, although he does convey the problems relating to dealing with the authorities and the health care system.'

Caroline says, 'Shaun writes about everyday practicalities but also weaves in and out of his family history and his recollections, learning more when he talks to an uncle and discovers old letters and photographs.'

John says, 'Shaun's book is a great introduction to what your life is about to become once you sign up to being a carer. There are lots of negotiations to be done. He emphasises the need for to-do lists to try and stay one step ahead.

'Shaun splashed out £40 on a

second-hand bike, but you might have your own ideas for what would make "me time" most important to you. He found internet dating an interesting idea but accepted the limitations life brings with a full-time caring role. Still, we can dream.'

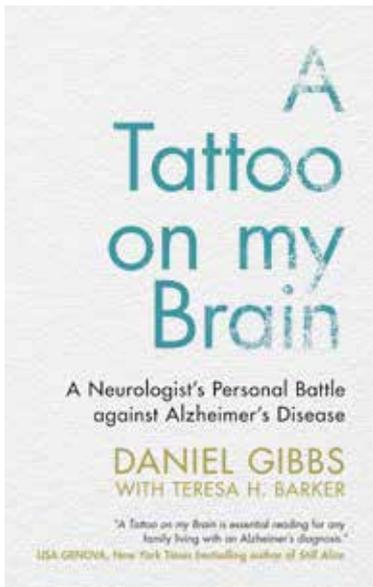
Maggie says, 'Shaun is honest about the difficulties faced, being a man caring for his mother (deemed to be "inappropriate"), the red tape of the role, being an advocate for his mother when she was hospitalised and the sheer loneliness and isolation the role brought, "a single parent to a single parent".'

Lessons learnt

'There are lessons for all to be learnt from the book, tips about "going with the person",' says Maggie. 'I liked his response to, "Who are these people?" when his mum was hallucinating – he responded, "I'm on to it, I'll let you know!"'

John adds, 'Love and Care had a profound effect on me. If you are facing the situation Shaun has highlighted, be kind and be gentle. You can't expect to get it all right at once. Just do the best you can and let the love take care of itself.'

Love and Care, by Shaun Deeney (Endeavour 2021), 336 pages, £16.99, ISBN: 9781913068462. Also available as an ebook or audiobook.



Book giveaway

We have five copies of *A Tattoo on my Brain* to give away – email magazine@alzheimers.org.uk by the end of 14 October quoting 'Tattoo' for a chance to win one (see p39 for terms and conditions).



Your turn

For the next issue, we invite you to read *A Tattoo on my Brain*, by Daniel Gibbs (Cambridge 2021), 254 pages, £18.99, ISBN: 978 1 108838931. Also available as an ebook or audiobook. Tell us what you think about this book by a neurologist who was diagnosed with Alzheimer's. Email magazine@alzheimers.org.uk by the end of 2 November so we can share it in our next issue.

LGBTQ+ resources

Support groups

Opening Doors London has three support groups open to members across the UK:

- Speak Out with Dementia is a weekly online peer support group for LGBTQ+ people with a diagnosis of dementia.
- Rainbow Carers Group is a twice-monthly online support group for LGBTQ+ people who are caring for someone with dementia.
- Rainbow Memory Café is a monthly group for LGBTQ+ people with dementia or who are worried about their memory, and their partners, friends and carers. It meets online and in person.

Email info@openingdoorslondon.org.uk for further information.

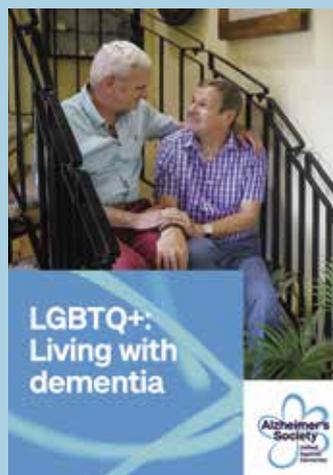
Greater Manchester LGBTQ+ Online Dementia Support Group is a new online peer support group for LGBTQ+ people affected by dementia. It meets monthly via Zoom. For details, call **0161 622 9252** or email maggie.hurley@ageukoldham.org.uk

The Dementia Project at Brighton & Hove LGBT Switchboard provides information and support to LGBTQ+ people affected by memory difficulties, cognitive challenges or dementia, and to their carers. Support is provided by phone, online and at meetups. Call John on **07783 760249** or email john.hammond@switchboard.org.uk

Advisory group

See p6 for news about the LGBTQ+ Dementia Advisory Group.

Updated booklet



The Society's LGBTQ+: Living with dementia (1511) booklet has been fully reviewed and updated based on feedback from LGBTQ+ people affected by dementia. There are new tips and advice, with guidance on getting the right emotional and practical support and on planning for the future. See alzheimers.org.uk/publications or call **0300 303 5933** to order.

Factsheet for carers

Our Supporting an LGBTQ+ person with dementia (480) factsheet has advice and practical tips on memory problems, getting support, planning ahead and more.

See alzheimers.org.uk/publications or call **0300 303 5933** to order.

'I have dementia and I've had my COVID vaccinations – do I really need to get a flu jab this year as well?'

Do I really need a flu jab?

After all the focus on COVID-19 over the last year and a half, flu might not seem as important as it used to be. But getting an annual flu shot is always a good idea if you're older or have a higher risk of complications from flu – and that includes people living with dementia.

The UK's COVID-19 vaccination programme has been a huge success – it's the main reason we can now mix more freely. However, COVID vaccines only protect against coronavirus and don't do anything to prevent flu.

You don't want flu

Flu can be serious at any age, but for a person with dementia it may cause delirium too. This can make someone become confused and agitated or withdrawn and drowsy in a short space of time. Although delirium would generally get better once the person recovers from flu, it could mean they're no longer able to do things they could do before.

Flu can also quickly turn into something more serious, needing a visit to hospital that could have been avoided otherwise.

Especially this year

Because there was so little flu around last winter, this year's wave is likely to start earlier and be worse than usual. It's also the first winter where the NHS will be coping with both flu and coronavirus while we're not in lockdown.

A person who has a flu shot lowers their risk of needing to see the doctor or go to hospital. Being vaccinated also cuts the risk of you infecting other people. This can make a big difference to helping NHS and social care services cope with the rise in seasonal infections. Every year the flu vaccine saves lives by stopping thousands of people from getting seriously ill from flu.

It's easy to get your jab

The best time to get your flu vaccination is between September and the end of November, though the earlier the better.

The flu jab is free if you are 50 and over (including if you turn 50 by the end of March 2022) or have a long-term condition. It's also free for anyone who's your main carer. If someone's not eligible for a free vaccine, many pharmacies offer a flu shot for under £20.

Most vaccinations can be done at local GP practices, care homes and community pharmacies, and it might also be available at some mass COVID-19 vaccination centres.

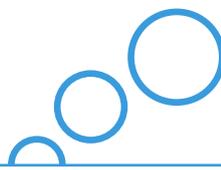
Photograph: Prostock-Studio



Get your flu jab

Get as much protection as possible for yourself and for others by booking an appointment for your free flu shot with your GP or local pharmacy.

Visit www.nhs.uk/flujab for further information and to find local pharmacies that offer the flu vaccine.



Music and memories

Music can trigger powerful memories and emotions for us all. Even when dementia causes memory problems, many people continue to remember tunes and lyrics. Reminiscing in this way can help someone communicate and lift their mood.



Playlists and games

Many websites and apps can be used to listen to music on a computer, smartphone or tablet, such as Spotify, iTunes and YouTube. You can also use these to make playlists of favourite tracks.

Playlist for Life provides advice and resources to help create playlists, see www.playlistforlife.org.uk/get-started or call **0141 404 0683**. Children and younger family members may enjoy helping too.

Reminiscing about music can be made into a game. Use playlists or CDs for 'name that tune' – play the first line of a song and see

whether someone can say what it is. Or try a game like Musical bingo, available from our shop – go to shop.alzheimers.org.uk or call **0300 124 0900**.

Playing and singing

People who previously learnt a musical instrument often find they can still play as their dementia progresses.

For singalongs, use a songbook or DVD of an old musical – usually available from libraries as well as shops. Search YouTube for karaoke videos or check your local cinema for dementia-friendly screenings of classic movies. Streaming services, like Netflix, might offer

the Hollywood, Bollywood or other musical you want.

People with dementia can socialise while singing familiar favourites at Singing for the Brain. These groups develop their own repertoire of songs from different eras, styles and cultures – see alzheimers.org.uk/singingforthebrain or call **0333 150 3456**.

Someone who can't sing or play an instrument might still enjoy humming, whistling, clapping or tapping their feet to familiar songs.

Visit alzheimers.org.uk/publications or call **0300 303 5933** for The activities handbook: Supporting someone with dementia to stay active and involved (77AC).

Over to you

Do you have any tips about music and memories that we could share next issue? Email magazine@alzheimers.org.uk by 4 November.

The great outdoors: What you said



nae sporrán, on Talking Point, says, 'My partner grew up in the forest and knew all the Latin names for plants before all this. She is not really mobile, but I like nature walks with my camera. I have a photo of a snowdrop (pictured) on the wall which she thought was real, but she was always happy to see it as a reminder of better days.'

LynneMcV says, 'During the warmer months my husband developed a huge passion and interest in the importance of bees, so we made sure to always seek out areas where they were busiest, as well growing things to encourage them into our own garden. The important thing was to take time to stand or sit and observe – what would be a 10-minute walk for others might take us 30 minutes or more – but we saw and shared so much during that time.'



Talking Point members' tips on supporting a person with dementia who's struggling to follow different rules and signs while out and about.

Knowing what to do

'My other half can't make the decision whether to wear a mask or not for himself, he waits until we are at the shop and can see what everyone else is doing. If I put my mask on before we get there, he will copy me.'

Unsure2021

'My dad has vascular dementia and struggles to remember to keep his mask on and what it's for. He doesn't understand the pandemic. We have to keep reminding him and, if he talks, he pulls it down as he thinks we can't understand him if it's over his mouth/nose. As a family we have all decided to keep wearing masks.'

Shazza61

'There's an added complication in that my husband sees on TV that you don't have to wear masks in shops, but we're in Wales where they're still mandatory.'

'Also, our son who's living with us at the moment had COVID and my husband kept mentioning our son's sore throat even though we kept saying it's coronavirus. When we were doing our PCR tests (negative, thank goodness) he just didn't understand even though he has Sky News on all day.'

DazeyDoris

'My mum wears a sunflower lanyard that we were given in M&S last year. I would recommend it as we've seldom been challenged about anything, most people respect what it stands for.'

Kaths

'I agree that the sunflower lanyard solved a lot of problems and stopped people judging and giving him a hard time about not being able to wear masks.'

jennifer1967

Sunflower lanyards are designed to let other people know that you may need additional help or time, whether that's because of dementia or another condition or disability that isn't visible. You may be able to get one by asking at your local supermarket, or you can buy one from www.hiddendisabilitiesstore.com for 82p plus £3 delivery.

Visit alzheimers.org.uk/talkingpoint to read more and join our online community.

Next issue

What advice would you give someone who fears they're one of the 'invisibles' – not around enough to help support a family member with dementia? Email magazine@alzheimers.org.uk

Radio and music player

We have a Relish Radio and Music Player for one lucky winner drawn from correct entries received by 9 November.



Q: The first radio stations to broadcast regularly in the UK were:

- A. Radio Caroline and Dread Broadcasting Corporation.
- B. Radio Reith and Marconi FM.
- C. 2MT (known as 'Two Emma Toc') and 2LO.

Farmhouse jug

We have a beautiful Forget-me-not farmhouse jug and two mugs for one winner drawn from correct entries received by 2 November, with a Forget-me-not mug and bauble for one runner-up.

Q: Another name for forget-me-nots is:

- A. Scorpion grass.
- B. Crab sticks.
- C. Remember-me-always.



Send us your answers with your name and address – email magazine@alzheimers.org.uk

Terms and conditions for competitions and giveaways 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.

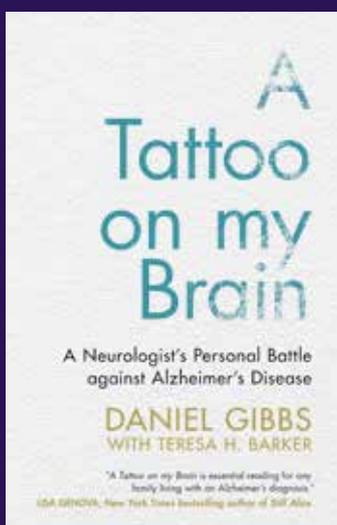
Jigsaw competition

M Lloyd in Shropshire won a Caribbean 1963 puzzle and V Dow in Surrey won a Friends in Lagos puzzle, while L Mitchell in North Yorkshire, M Julian in Greater London, M Coll in West Yorkshire, S Thomas in Cardiff and M Turner in Wiltshire each won a Sister Grace cotton tea towel.

Answer: Soursop is a fruit.

Book giveaway

See p35 for a chance to win a copy of *A Tattoo on my Brain*, by Daniel Gibbs.



Memory Walk T-shirt competition

A Chandel in West Midlands, S Dowie in Isle of Wight and T Jolley (Snr) in South Yorkshire each won a Memory Walk T-shirt, while T Jolley and S Poskitt in South Yorkshire, M Stephenson in Nottinghamshire, D McKillen in County Antrim and R Lee in Warwickshire won Memory Walk wristbands. **Answer: Memory Walk is free to sign up for and open to everyone.**

Book giveaway

The five readers who each won a copy of *Love and Care*, by Shaun Deeney, were M Woodhouse in Suffolk, L Booth in West Yorkshire, T Jolley in South Yorkshire, M Stephenson in Nottinghamshire and D Gregory in West Midlands.



Visit our Online Shop

A fabulous range of Christmas essentials such as cards and wrapping paper, gifts and games as well as assistive products and forget-me-not goodies.

Call **0300 124 0900** (local rate) to ask for a copy of the catalogue, or shop online at shop.alzheimers.org.uk

Last postal date for standard delivery is 17 December.

PS. If you shop online with Amazon Smile your purchase will still help support us.

Each purchase from our shop directly supports families affected by dementia