

# Dementia together

August/September 2021  
Alzheimer's Society's magazine

## Talk about tomorrow

Advance care planning

## Better sleep

Supporting rest



## Take courage

Continuous learning

## Also in this issue

Road to recovery

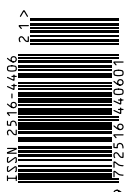
Dealing with debt

The 'perfect carer'



# You can fight it

A change of attitude



# Welcome



**L**ooking at the articles in this magazine, there's a lot of talk about fighting back, taking courage and looking ahead.

If you're dealing with your own or someone else's dementia every day, it doesn't always feel like these things are an option. Sometimes we need to accept when something simply can't be done, or that not feeling good is a part of life (not the only part, but a part nevertheless).

There are also times when seeing others going through something similar can help us feel less alone, or when new ideas can inspire us and make us feel more in control. We don't want to miss any of these opportunities to make a real difference.

Whether you're living with dementia, caring for someone who is, or supporting the cause in another way, we want to get the most powerful stories and useful information to you in every issue of the magazine. If you have any feedback, then let us know so we can continue to make it as relevant and helpful as possible.

**Danny Ratnaike, Magazine Editor**

**Need support? We're here for you – see p18.**

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

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**£50 means 312 people can access Talking Point, our online community, where a trouble shared can be a trouble halved. Please give what you can today.**



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## Fix social care

On his first day in Downing Street, the Prime Minister promised to 'fix social care once and for all', but we're still waiting. Enough is enough.

Over 135,000 of you signed our #CuretheCareSystem petition, which was handed in to leaders in Wales, England and Northern Ireland. Alzheimer's Society has also joined almost 50 organisations in the Care & Support Alliance in telling the Prime Minister to keep his promise.

With your support, we're keeping the pressure on the government to act now for those affected by dementia! We won't stop until our voices are heard. Help us to achieve meaningful change – visit [alzheimers.org.uk/campaign](https://alzheimers.org.uk/campaign)

## Political priority

With Northern Ireland Assembly elections on the horizon, Alzheimer's Society is calling on political parties to make dementia a standalone priority in the ongoing reform of adult social care.

We also want candidates to commit to full funding for the Regional Dementia Care Pathway – a plan of action for high quality dementia services in Northern Ireland.

We need your help to convince them. Your experiences of dementia provide the most powerful way of making our case.

Share your story – visit [alzheimers.org.uk/NI-campaigns](https://alzheimers.org.uk/NI-campaigns)

## Coronavirus: Road to recovery

Alzheimer's Society is calling for a clear strategy to help people with dementia in the UK recover from the impact of the pandemic.

Many people with pre-existing long-term health conditions have deteriorated faster than usual since the pandemic began, as highlighted in our recent report, *Moving forward stronger*. As well as disruption to local services like occupational therapy, people with dementia have been affected by a lack of social contact and delays in diagnosis.

The report was produced in partnership with other charities and with groups representing healthcare professionals. It calls on the government to fund a two-year rehabilitation strategy to ensure that people get the therapeutic support they need. We also want to see local rehabilitation plans put in place.

## Hundreds and thousands of thanks

A huge thank you to everyone who bought, baked and donated this Cupcake Day. The money you've raised will help provide life-changing care and fund world class dementia research at a time when it's never been needed more.

We hope you had a wonderful day celebrating and enjoying delicious treats – thank you for baking a difference!





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## Memory Walk is back!



Walk for a world without dementia by taking part in Memory Walk this autumn. Memory Walk is a family-friendly sponsored walk and a fantastic way to make a real difference to people affected by dementia.

Join thousands of others in locations around the country by signing up to one of 20 walks taking place from Belfast and South Shields to Cardiff and Brighton. It's free to sign up and accessible to all, and each walk will follow government COVID-19 guidelines.

If you prefer, you can walk your own route on 19 September. You choose the location, the distance and who you take part with, whether on your own or with friends or family.

However you choose to take part, every step you take will bring us closer to a world without dementia. Who will you walk for?

**Sign up for Memory Walk at [alzheimers.org.uk/memorywalk](https://alzheimers.org.uk/memorywalk) or call 0300 330 5452.**

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## Garden of memories

A show garden inspired by the experiences of people affected by dementia went on display at RHS Hampton Court Palace's recent garden festival. The 'Down Memory Lane' garden was based on memories of staff at garden centre firm The Blue Diamond Group, including lead designer Anna King, whose father has dementia. They also launched a beautiful orange-copper 'Down Memory Lane' rose, with £1 from each sold through Blue Diamond Garden Centres and Fryer's Roses coming to the Society – see [www.fryersroses.co.uk](https://www.fryersroses.co.uk)



## Directions

**L**ike the lovely summer bees, things are really buzzing at Alzheimer's Society! A huge thanks to the hundreds of you who've been sharing your wisdom about where the Society really adds value – your ideas are shaping our next strategy for April 2022 onwards.

Since May's Dementia Action Week, we've kept up pressure on the government to announce meaningful reform of the social care system. That means improving care quality (no more 15-minute visits!) and access, as well as a solution to the knotty problem of who pays.

As we prepare for Northern Ireland Assembly elections and get Welsh Parliament members' commitment to social care reform, we're also heading toward a new national dementia strategy in England. We want an ambitious five-year government plan to deal with big issues like the lack of investment in research and having no clear evidence or understanding on most aspects of dementia.

We're not backing down on holding the government to account to create the best possible environment for people with dementia to live their best lives, with us beside them all the way.

Look out for our new impact and accountability report on our website from early September, which will tell you everything you need to know about what we achieved last year – and the things we didn't. In the meantime, keep safe and enjoy your summer!

**Kate Lee, Chief Executive Officer**  
**[@KateLeeCEO](https://twitter.com/KateLeeCEO)**

## In the press: Working out risk

Several media outlets recently reported on an online calculator that can tell you what your risk of getting dementia is. But how accurate is it?

Working out a person's chance of developing dementia is usually done by healthcare professionals, because it involves complex techniques like genetic testing and assessment of other risk factors.

Researchers in Canada wanted to make it easier and quicker for people to find out their risk. Their calculator uses information such as age, ethnicity and how active someone is, to give over 55s their risk of developing dementia in the next five years.

Clare Jonas, Research Communications Officer at the Society, said, 'Risk calculators like this are becoming more and more accurate as our understanding improves.'

'However, this calculator can't predict risk perfectly and there's still no sure-fire way to predict whether someone will go on to develop the condition. It doesn't include all the different factors that can affect your risk level, and it's based on whether the people who took part were diagnosed with dementia, not whether they had it.'

'This is a problem because not everyone with dementia will get a diagnosis, so the calculator may underestimate the risk.'

'If you're concerned about your risk level you should always speak to your GP, so that they can offer you more help and information.'

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

## Games at home

A programme of specially adapted games has shown how people with dementia and other conditions can stay active in their own home.

The Home Games, based on the decathlon, saw people with long-term health conditions – including dementia – take part in events such as laundry basketball, watering-can wander and the sock put.

Paralympic athletes took their teams through 10 weeks of The Home Games alongside their own training for this summer's Tokyo Paralympics.

The Home Games are part of We Are Undefeatable, a campaign supported by Alzheimer's Society that inspires people with long-term health conditions to lead more active lives.

Tommy Dunne participated in the programme and said, 'Dementia affects not only my memory, but also my mood and spatial awareness, so it can be tempting to just sit at times. Being part of The Home Games has shown me that keeping active even in small ways can really help, particularly in raising my mood.'

**For more about We Are Undefeatable and staying active, visit [alzheimers.org.uk/active](https://alzheimers.org.uk/active)**

## Use your voice

Use your experience of dementia to influence the work of Alzheimer's Society and other organisations.

In the past year over 400 people affected by dementia got involved with more than 900 activities – why not join them?

To find out more, please visit [alzheimers.org.uk/dementiavoice](https://alzheimers.org.uk/dementiavoice)

## Northern Ireland conference

Join us at our conference discussing the future of dementia services and care in Northern Ireland.

Registration is now open for the virtual event, which takes place on 21 September – World Alzheimer's Day.

Guest speakers include Minister for Health Robin Swann and former carer Emily Wilson.

**Register for the conference at [alzheimers.org.uk/ni-conference](https://alzheimers.org.uk/ni-conference)**

## Crafts for children



Forget-me-not Crafts is a new initiative encouraging children to create forget-me-not flowers and raise funds to help beat dementia.

We'll email you guides for card-making, knitting, baking biscuits and painting, or your children can make their own forget-me-nots in any way they want.

When they've finished crafting, help them collect donations for their creations from friends and family. Every pound raised will help us support anyone affected by dementia.

To register visit [alzheimers.org.uk/forget-me-not-crafts](https://alzheimers.org.uk/forget-me-not-crafts) or call 0330 333 0804.

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## Supporters honoured

Congratulations to our high-profile supporters who were recognised in this year's Queen's Birthday Honours. Actor Jonathan Pryce has been awarded a knighthood for his services to drama and charity, while Society Ambassador, choreographer and theatre director Arlene Phillips was made a Dame for her devotion to dance and charity.

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## Listen up!

Hear people with dementia tell us their stories in the magazine's audio interviews. Our 20th interviewee in this popular series is Michael Andrews, who lives with a rarer form of dementia called posterior cortical atrophy (PCA).

Listen to Michael and others at [alzheimers.org.uk/podcast](https://alzheimers.org.uk/podcast)



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## Writing a will

We can help you get an up-to-date will in a way that works best for you – in person with a local solicitor, online or over the phone. When you write or update your will, you can also do something incredible – leave a legacy to help us make sure no one has to face dementia alone.

Visit [alzheimers.org.uk/wills](https://alzheimers.org.uk/wills) or call **0330 333 0804**.

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## Aducanumab approval

The Society has described the US approval of a new dementia drug as 'promising', while underlining how more drugs need to be developed because this one may only benefit some people.

US regulators recently approved aducanumab for people with Alzheimer's, though it's only been tested in the early stages of the condition.

Richard Oakley, our Head of Research, said, 'We await the opinion of the European Medicines Agency and the outcome of any application made to the UK regulatory authorities, to give clarity to people with early Alzheimer's disease in the UK. Whatever the outcome of their decision, this is just the beginning of the road to new treatments for Alzheimer's.

'As this drug may only benefit a proportion of people in the early stages of Alzheimer's disease, there are hundreds of thousands more who may not be eligible. We must keep searching for drugs for all stages of Alzheimer's and for other types of dementia.'



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## Forget Me Not flower badges

We've been celebrating a successful start to our new Forget Me Not appeal. People donated to Alzheimer's Society in return for a flower badge to be worn during June and beyond, raising awareness as well as vital funds.

We've now sent out nearly 260,000 badges, which has raised £200,000 and counting! The Forget Me Not appeal will return next June, though you can still donate and receive a badge for this year.

To donate visit [alzheimers.org.uk/forget-me-not-appeal](https://alzheimers.org.uk/forget-me-not-appeal) or call **0330 333 0804**.

## Don't miss...

Edward in Oxfordshire, who has posterior cortical atrophy, says he has 'no alternative' but to be positive. [See p12.](#)

Karen and Rob, in north Wales, are leaving a gift to Alzheimer's Society in their wills. [See p13.](#)

John in East Sussex is helping to improve support for LGBTQ+ people affected by dementia. [See p14.](#)

Meet Kirstie, Sector Engagement Policy Manager, and Zoe, our Director of Operations. [See p19 and p21.](#)

The 3 Nations Dementia Working Group has been leading conversations about planning for end of life care. [See p26.](#)





## Quick read

Mary Best, 70, is maintaining a positive outlook and embracing new opportunities following her diagnosis with Alzheimer's in 2017.

For Mary, receiving a diagnosis meant she knew what was wrong and how she could fight it.

Mary, who lives in Belfast, stays active and involved by supporting the work of Alzheimer's Society, attending a day centre and going on courses.

She encourages anyone who is worried about their memory to get it checked out, adding that there is life after dementia.



# You can fight it

An Alzheimer's diagnosis has meant a change of attitude and outlook for Mary Best. **Gareth Bracken** meets a woman who is embracing new opportunities.

**I** don't believe in looking forward – I can't know what I'll be like in a year's time, so why worry about it,' says Mary Best, who has Alzheimer's disease. 'The more you worry, the worse you'll be, is the way I look at it.'

Mary, who lives in Belfast, has adopted a positive attitude and approach, which includes being open about her diagnosis, proactively seeking support, and staying as active and involved as possible.

'You have to come to terms with it,' she says. 'Take each day as it comes and be thankful for it.'

## Foster family

Mary, now 70, grew up near Enniskillen, County Fermanagh, in the south-west of Northern Ireland.

'I was fostered when I was two years of age – it wasn't good,' she says. 'In them days, you were just given to people and they got money for looking after you. They didn't treat me too well.'

Mary married in her mid-20s but after that ended in divorce, she was cut off from her two children and didn't see her daughter Fiona for 10 years.

'There was always a stigma that foster children weren't good to their own children,' she says. 'But thankfully Fiona and I are as thick as thieves now.'

Mary was a prison officer in Holloway prison in London for three years in the late 70s, but mostly worked in care homes, looking after older people.

'It was hard work, but I really enjoyed it,' she says.

Mary has five grandchildren, including one in Australia. Her second husband, Henry, died before her dementia diagnosis.

These days, Mary enjoys reading, crocheting and playing card games online.

'Anything to keep my brain occupied,' she says.

## Blank map

Mary first noticed problems with her memory when she started to struggle with her spelling.

'I was always quite good at it, but then I was asking my husband and daughter how to spell things that I should have known,' she says. 'I was also making stupid mistakes when driving, like a

missed turning. I would get agitated at myself.'

Having felt 'very depressed and frustrated' at what she was experiencing, receiving a diagnosis of Alzheimer's disease in 2017 was actually a relief.

'I knew there was something wrong, but I didn't know what,' says Mary.

'When I was told, I knew how it was, how to fight it. Before that it was like holding a blank map, I had to go somewhere but there were no directions.'

## Gain something

Mary continues to face challenges with her short-term memory, which prompted a change in lifestyle.



Mary with granddaughter Charlotte-Louise and grandson Logan.

‘I switched off the TV and started using my brain more,’ she says. ‘I think that’s the best way to fight it – don’t let your brain stagnate.’

She has also altered her outlook.

‘I used to worry about what people thought, but now I just think, “You only live once,”’ says Mary, who also uses hearing aids and a walking stick, as well as a rollator for longer walks.

‘I’m a great believer that if you lose something, you gain something,’ she continues.

‘If I hadn’t had something, I wouldn’t have met the people I’ve met – people with dementia and Alzheimer’s Society staff – who have been more than brilliant.’

### Have your say

The suggestion to contact Alzheimer’s Society was made by Queen’s University in Belfast, who Mary had approached about donating her body to science.

‘The Society have been a fantastic help,’ says Mary, who is involved with our work in several ways.

She is a member of a Dementia Voice local group, made up of people with dementia who influence Alzheimer’s Society’s and other organisations’ work. They

do this by sharing their personal experiences, knowledge and skills to shape a wide range of projects and topics chosen by them.

‘It’s good to have your say,’ says Mary, whose group has given feedback about a new bank card and tested out mobility scooters.

Mary was also a judge for the Dementia Friendly Awards and has been to Stormont to speak to politicians.

‘I was there to give my input about what it’s like to have Alzheimer’s and what I thought they should be doing,’ she says. ‘It was good to tell my story and give them an insight into what people with dementia are going through.’

‘Sometimes I think politicians are in a wee bubble – they don’t know how the other half live. If they don’t know anything about it, they can’t be expected to do the things they need to do.’

### Providing purpose

Mary enjoys going to a local day centre for people with dementia, which has been a valuable source of support.

‘Before that I was sitting in the house, thinking what’s the use in getting dressed,’ she says. ‘It gives you purpose, something to look forward to. I’ve made friends and the staff are brilliant.’

‘That was the only good thing during the last lockdown, that the centre reopened in April. I got a bit depressed before that.’

Although the pandemic has affected her activities and interaction, Mary – who has had both of her COVID vaccinations – is trying to keep things in perspective.

‘People missed going on holidays, but I missed having a hug, the small things, she says. ‘I also miss going places through Alzheimer’s Society, but at the same time, people have had it worse than me.’

### Keep going

Mary receives excellent support from her daughter and son-in-law, which has continued through the pandemic.

‘Fiona gets my shopping and Joe does the weeding and gardening. There’s nothing they wouldn’t do for me,’ she says. ‘Sometimes I feel awful even having to ask, but I don’t know what I’d do without them. I’d be lost.’

Mary also appreciates regular phone calls from Margaret, a support volunteer who she was initially put in touch with by Alzheimer’s Society. Before the pandemic they would meet for coffee or go to the cinema or garden centre.

‘I don’t have any sisters, but Margaret is my age,’ says Mary. ‘For people living on their own, or for somebody with nobody, it’s good to have somebody.’



Mary and her daughter Fiona.

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



Mary currently attends community development sessions at a Women's Centre, where she gives her views on local issues. She is also on a photography course that will see her work form part of an exhibition.

'While you can keep doing something, you do it,' she says.

### Not the end

As we hopefully continue to emerge from the pandemic, Mary feels that people with dementia can play a vital role in making others more aware of the condition.

'Dementia awareness can be lacking,' she says. 'It's got a lot better than what it was, but I think the pandemic has set things back. People are more into their own problems, like have they got a job.'

'But there's a lot more can be done and some of that's up to us.'

Mary also sees no reason for people to hide their dementia diagnosis from others.

'What's the use?' she says. 'What have you to worry about letting people know?'

And Mary advises anyone who has concerns about their memory to take positive steps towards getting the right help and support.

'If someone's worried there's something wrong – like I was – get a diagnosis. A quicker diagnosis means more peace of mind, then you can fight it,' she says.

'It's not the end of the world. There's a life after dementia.'

Mary with (clockwise from bottom left) granddaughters Charlotte-Louise and Chelsea, daughter Fiona and her husband Joe, and grandson Logan.



Photographs: Brian Morrison

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



### What can you do to help?

You can inspire people like Mary to speak out about dementia by donating to help run Dementia Voice groups. Please **give what you can today**.

# 'I'm still me'

**Edward Bushnell** in Oxfordshire, who is 62 and has posterior cortical atrophy, says he has 'no alternative' but to be positive.

**P**osterior cortical atrophy (PCA) affects my life massively. I do try and do things to combat the symptoms.

I use Headspace, a mindfulness app, every day. I get quite a lot of anxiety. Headspace helps me calm down and be more myself. I get incredibly anxious about various things, though I never used to. If anything, it's getting worse. I'm on a drug called citalopram, an antidepressant. I take one a day, it helps me be calm – calmer anyway.

I also use Lumosity, a 'brain training' app, every day to keep the cogs whirring as long as I'm able to.

I don't have vision problems, which are common with PCA. I'm scheduled to see an optometrist in future, but at the moment everything is OK with my vision, fingers crossed.

## No alternative

It was my wife Samantha who first noticed I was struggling with things. The thing that manifested itself initially was my co-ordination – not being able to put things together properly.

I lost my job. I was head of internal audit for a financial services firm in London. I loved it. That's all gone now.

There isn't an alternative to being positive in my world. I choose to remain with a positive outlook – I'll fight that for as long as I'm able to do so.

The support from my wife is nothing short of fantastic, I love her to pieces. I'd be up a gum tree without her!



Edward and his wife Samantha.

monthly. We discuss all that's good in the world and have a good laugh. You walk away with your sides aching. That kind of thing is vital to keeping going for as long as I possibly can.

## Fundamental

Getting the message about dementia out there is really important. I regularly give my local MP a really hard time about dementia and dementia support. It's about raising awareness, particularly about the rarer dementias – it's fundamental.

I'm still me. The most important thing to do is not give up. There's still a life after a diagnosis.

## Keeping going

During the pandemic, one thing I've been doing every day is go out and achieve 10,000 steps a day to keep myself fit and get fresh air. Those are the sort of things that help me and are fundamental to my ongoing wellbeing.

The main thing is, I get confused. That's the bit I struggle with. That has its frustrations.

We've had both COVID vaccinations. I can't wait for life to get more back to normal. I'm looking forward to it very much. We've got a holiday booked to Scotland.

Virtual support groups run by Rare Dementia Support and Dementia UK have been fantastic, incredibly helpful.

I'm in a group where all of us have PCA and we get together



# A better future

**Karen Beattie** in Abergele in north Wales explains why she and her husband Rob are leaving a gift to the Society in their wills.



**M**y husband Rob was diagnosed with Alzheimer's in 2017. It's a cruel disease, especially as he understands what's happening. He was diagnosed at 62, relatively young, and gets very frustrated and very down.

He goes off and doesn't take his phone – I've had to phone the police and they bring him back. We came home to Wales from Ireland after Rob had to give up work. I also gave up work to be his full-time carer.

Since lockdown, he's deteriorated a lot. He's disorientated around the house and forgets his words, he gets muddled up. But then some days he's spot on and you honestly wouldn't believe there was anything wrong with him.

## Everything we can

We're Dementia Friends Champions and, before the pandemic, would go round schools and colleges talking about dementia.

Rob was in the RAF for 25 years and can speak better when he's in his uniform. Hopefully things will change and we can start doing it again, as dementia awareness is so important.

We've done media work, fundraising like Cupcake Day and

dementia-friendly audits at Bangor University. We do everything we can to make a difference or raise awareness.

## Find a cure

After Rob's diagnosis, we decided the first thing to do were lasting powers of attorney (LPAs) and then wills. We were going through them with a solicitor and Rob said yes straight away to leaving something to Alzheimer's Society. You can't take it with you!

The process was easy through our solicitor, but there are ways that Alzheimer's Society can help people to get an up-to-date will.

We've pledged half of our house to the Society, to fund research into a cure – we need a cure. We know it's too late for us, but anything we can do to stop others going through this would be great.

I would encourage others to think about leaving a gift in their will. Even if it's a small amount, it will still make a difference.

**For more about leaving a gift to Alzheimer's Society in your will, visit [alzheimers.org.uk/wills](https://alzheimers.org.uk/wills) or call 0330 333 0804.**

## Call and play

Alisha, who adapted versions of classic games that her grandma could play with her over the phone, is sharing them online. Anyone can print out, post and enjoy versions of Battleships, Connect Four and more on paper over an ordinary phone. Visit [www.quickquarantinegames.com](https://www.quickquarantinegames.com)

## Reggae and more

The BBC teamed up with Ronald Amanze to produce a one-hour Reggae Memory Radio show, with selected tunes, clips and conversations, and an accompanying activity sheet.

This joins a range of shows themed by decade and location, including in Welsh, Irish and Scottish Gaelic languages. Find them on the BBC Sounds app or see [www.bbc.co.uk/musicmemories](https://www.bbc.co.uk/musicmemories) and click Memory Radio.



## 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](https://dementiafriends.org.uk) to get involved.

# An affirming space

**John Hammond** in Brighton tells us how he's drawing on his experiences to improve support for LGBTQ+ people affected by dementia.



**W**hen my mum was diagnosed with Alzheimer's, I was completely lost. I was given a leaflet and the consultant said, 'Read this, it will tell you everything you need to know.' But it didn't.

Before her diagnosis, I had no understanding or appreciation of dementia. As became apparent, dementia is complex and it affected Mum in many ways.

I contacted Alzheimer's Society. They helped me throughout. An incredible dementia support worker provided a listening ear about my mum's rapid change in her condition. I could keep checking in with them to ask questions about Mum's symptoms. This was very reassuring.

I wanted to give something back, desperately, as soon as I was able to, and I've been volunteering with the Society for around five years. I believe wholeheartedly in its approach and wanted to be a part of that.

I've helped to co-facilitate carer support sessions and peer support groups. I'm also involved with the Research Network and Volunteer Advisory Panel. Most recently I've been working with Alzheimer's Society in thinking how the LGBTQ+ area of its online community, Talking Point, can be more engaging.

## Specific support

I'm also Operations and Development Manager at Brighton & Hove LGBT Switchboard, and we saw the need for support that's specific to LGBTQ+ (lesbian, gay, bisexual, trans and queer) people affected by dementia.

Our Rainbow Café, born from our older person's project, provides an opportunity for LGBTQ+ people who are affected by dementia to support each other.

Some people have had very negative experiences of services. Many have lived through times when their identities will have been criminalised or pathologised. LGBTQ+ people disproportionately live alone and are disproportionately affected by social isolation, mental health conditions and alcohol use – all risk factors for dementia.

I find that many of our Rainbow Café members have a family of choice rather than a family of origin.

## Your entire self

The Rainbow Café is a safe, affirming space for LGBTQ+ people to come together. It's very welcoming, and there's no need to keep coming out. You can

be free, be your entire self in a support service. Dementia is tough, but there's a certain amount of celebration at our social meetings – celebrating people's life stories.

At Switchboard, we pride ourselves on working with Alzheimer's Society and many other organisations. We provide training and awareness, we're partnering with researchers and we're currently extending the Rainbow Café into West Sussex as well. It's an expanding project – it's exciting!

For our **LGBT: Living with dementia (1511) booklet** and **Supporting a lesbian, gay, bisexual or trans person with dementia (480) factsheet**, see [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) or call **0300 303 5933**.

To find out more about Brighton & Hove LGBT Switchboard's Rainbow Café, visit [www.switchboard.org.uk](https://www.switchboard.org.uk) or call on **01273 234009**.



# Meet the researcher: Jessica Budgett

Programme Manager at the NIDUS (New Interventions for Independence in Dementia) study at UCL in London.



## Favourite things?

- Film – Little Miss Sunshine.
- Way to spend time – I've recently started open water swimming and love it!
- Memory – I feel very nostalgic for live music so would have to be watching the singer Lizzo perform at Glastonbury in 2019.

## Why dementia research?

Both my grandfathers had dementia and, during my MSc in cognitive and clinical neuroscience, I worked as an assistant psychologist in a memory

clinic. The stories of people I met there really moved and motivated me to work more with people living with dementia in the NHS. Then, after working on dementia studies at UCL with some great teams, I felt inspired to continue with research.

## How has Alzheimer's Society supported your work?

Alzheimer's Society funds the NIDUS (New Interventions for Independence in Dementia Study) programme that I manage, which is led by Professor Claudia Cooper at UCL.

The Society has supported us in so many ways – Research Network volunteers worked with us to design our new support programmes, and they help us to ensure our findings make a real difference to people affected by dementia. I also feel very lucky to be doing a PhD funded by Alzheimer's Society.

## What are you currently working on?

Most people with dementia want to live in their own homes for as long as possible, with family and homecare support. We're testing the effectiveness of NIDUS-family – a way of providing psychological support for people with dementia and family members caring for

them. It aims to help people keep their independence and a good quality of life at home for longer.

In my PhD, I'm looking at how we can use the personal goals of carers and people living with dementia to decide if our support has made a meaningful difference to them. This is instead of using standard questionnaires that ask everyone the same things.

Dementia symptoms vary greatly and so do the ways people perceive different aspects of life. It's important that researchers can measure whether support has affected people's lives in ways that mean something to them.

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

If shown to work, we'd like to see how NIDUS support can be adapted and implemented in practice. I'd like to continue working to improve support from family members and paid carers, as we know how important this is in enabling people with dementia to live well.

## Join Dementia Research

If you're interested in taking part in great studies like NIDUS-family, please call **0333 150 3456** and ask for Join Dementia Research or visit [www.joindementiaresearch.org.uk](http://www.joindementiaresearch.org.uk)

# How I enjoy reading

We ask people about how they keep active and well, whether they have dementia or not. This issue, we hear about reading books, news and more.

## Helen Mayne, 55 in North Tyneside



I love reading books by LJ Ross, set in Northumberland and the North East. I read on Kindle and I play audio books

when driving around in my job. Reading is my way of relaxing after a busy or stressful day, and I read if I cannot sleep.

## William Payne, 61

I read fiction and non-fiction, literary and political magazines and newspapers daily.

Reading has provided relaxation and the facility of taking my mind away from preoccupations which caused anxiety.

I set aside at least half an hour each day to read without being interrupted or allowing myself to be distracted.

## Sarah Williams, 56 in East Sussex

I wait for the authors I enjoy to bring out new books and buy them as soon as they do. I often buy books from a charity shop from other authors and then donate them back when I have read them.

Reading is a good way to distract you when you have negative thoughts running around your head, it is amazing how reading a book can have a positive impact on how you feel.

## Anna Finlason, 67 in West Sussex



From when I was a child, I've always loved reading. I own a Kindle and have several books on it, but I also tend to go online

to read the news and anything else that interests me. I enjoy reading to my grandchildren to encourage a love of reading.

Reading is a pleasure and a way to lose oneself in the story. It opens up a world of knowledge and can be done anywhere at any time.

## Patrick Hawkins, 79 in Kent

I keep myself fully occupied by reading good literature, news items and following sport, cricket, rugby union and football, also gardening! This helps to keep my mind and body active and helps in my caring role as carer for my wife, who now has advanced stage Alzheimer's.

I have studied dementia over the past nearly nine years through the excellent online courses provided by FutureLearn and literature provided by Alzheimer's Society.

## Philip Bettles, 67 in Northamptonshire



I just feel so happy reading, and contented. It reduces stress and expands the mind, keeps the old grey matter lubricated.

## Martin Corrick, 75 in Hampshire with Alzheimer's



Reading, writing and teaching literature was a major aspect of my working life and remains important to me. I have a sailing

yacht and normally spend as much time as I can aboard her, but COVID-19 prevented this in the last year.

'Ambler' was my first choice as a place to read, write and draw, as well as enabling me to explore the coasts of the UK and nearby countries. COVID plus my dementia has severely restricted this way of life.



## 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](https://www.nhs.uk/livewell) for wellness advice for everyone.



# Q&A: Liz Brown

**Liz Brown** in Worcestershire, aged 75 with vascular dementia.

## **What's changed most since your diagnosis?**

Since my diagnosis my life has changed in many ways. Lots of things that I used to do without thinking are now, on the whole, much more difficult. It is hard to accept that my future is now so unknown.

## **What would you take to your desert island?**

I love music – all sorts of music – and poetry, which I love to read and write. I hope I'd have the opportunity to relax and enjoy my favourite things. To do this, I'd want to take books, paper and pens, but also a radio. It would be impossible to choose between them!

## **How has Alzheimer's Society helped you?**

Over the last years, it's been part of the rock that I've relied on. I've needed help with all kinds of things. I'm blessed with two volunteers – Tracy and Liane. I miss Tracy taking me out every week, though she phones instead, and Liane has called me every week since the pandemic started. The Society gives me the help that no one else can, and it has done right from the start.

## **What song or tune sums up your life so far?**

Hero by Mariah Carey. From listening to that, I feel that somewhere inside I have got the strength to carry on. The song points out that the hero lies in you – it's good to listen to when things feel hopeless, it's a very strong song.



If you have dementia and would like to answer our questions for a future column, email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk)

## **What single thing improves your quality of life?**

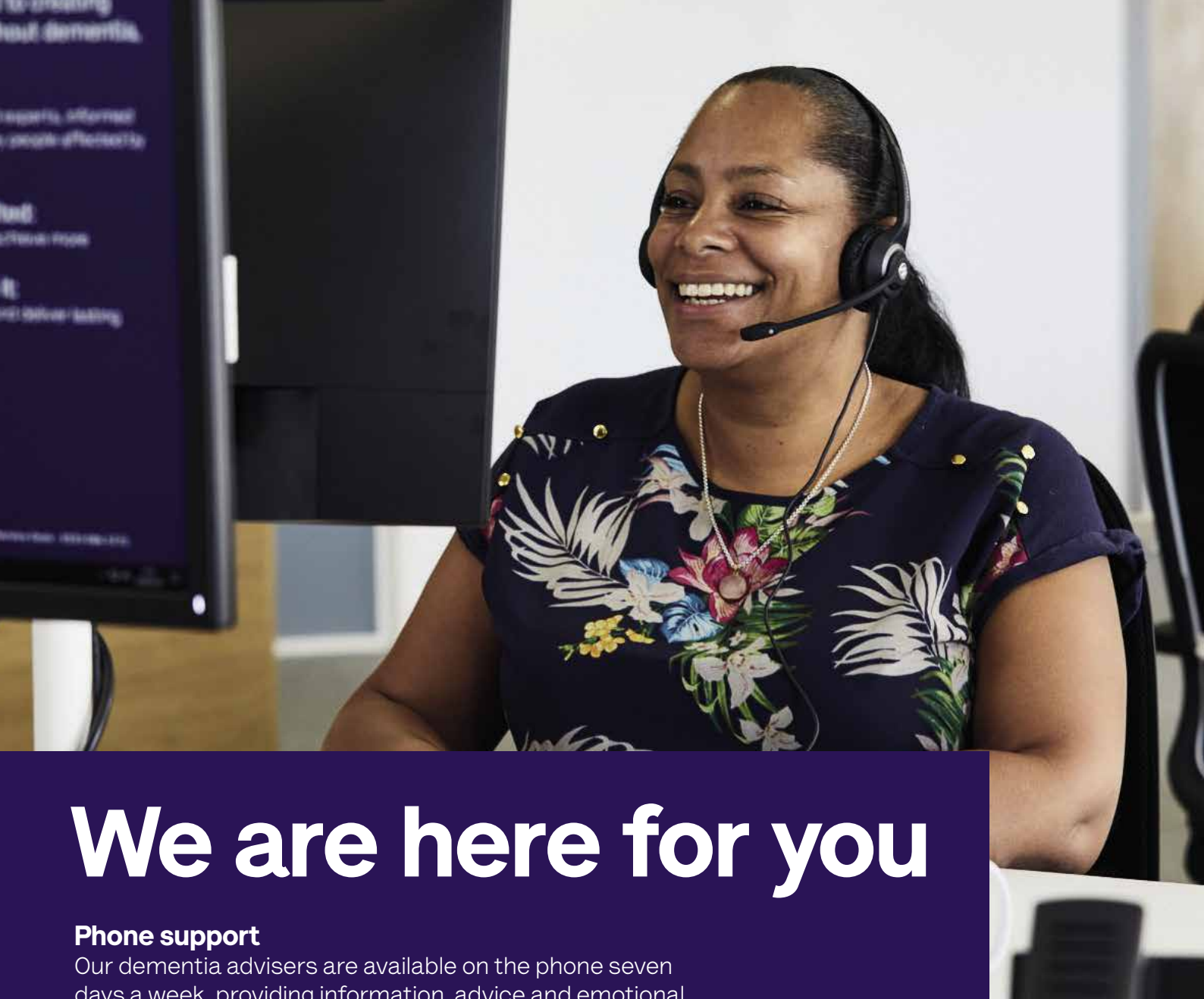
That's easy – my daughter, who cares and supports me through the good times and, especially, the bad. We do things together, she makes me laugh and she is my rock. I am very lucky!

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

I'd choose a part of my life – my teenage years. All the starts and new beginnings, solid friendships, time to relax and look forward to the future. Starting out – that for me was a good time.

## **What is your most treasured possession?**

My motorised wheelchair, which helps me maintain some independence and a chance to be part of life. I call her Bertha, my best friend, and I've had her nine years now. Even with my limitations, she gives me the ability to pop to the shop, go to the park to watch the ducks – gives me a little bit of freedom.



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

Person living with dementia





# All change

**Kirstie MacLean Kalonji, Sector Engagement Policy Manager, shares how people affected by dementia are influencing vital change.**



**In the four years I've been at Alzheimer's Society, my focus has been on helping to make a real difference to people affected by dementia in their everyday lives. Getting their concerns heard by organisations across all sectors is a vital part of this.**

Transport is a particular priority at the moment, but there are so many other aspects of life that we've been working on too. Making sure that people can still get face-to-face and telephone support as more services move online is an increasingly important area for us.

Working closely with our Dementia Voice team means I can gather viewpoints from a range of people living with dementia, their families and carers. This highlights the challenges that people face in real life, so we can help different sectors understand what they need to do to have a positive impact.

## Better journeys

Many people have had negative experiences on public transport because of a lack of understanding about dementia from other passengers or staff. People affected by dementia have made it clear to us that COVID-19 has only increased their concerns.

We're supporting the relaunch of the Department for Transport's 'It's Everyone's Journey' campaign. This promotes positive behaviour on public transport, including being patient and ready to help your fellow passengers.

People affected by dementia have reminded us that – whether there's a pandemic or not – how we choose to behave and treat others is a priority. This is especially true when people are often rushing about, intent on getting to their destination!

We've also worked on new guidance for bus and train staff. This highlights many important points, such as understanding that not all disabilities are visible and that many people will need them to communicate slowly and clearly.

## Not all online

So many activities and services had to go online due to coronavirus, and this was incredibly helpful for many of us.

However, some people aren't able to take advantage of online options, and many who've had to do so would much prefer returning to in-person contact in future. There's a similar situation for people who want to continue using cash for purchases instead of cards or online payments.

When Transport for London stopped accepting cash in 70% of its stations during the pandemic, we used feedback from people affected by dementia to convince them to reverse this. They also dropped plans to make all stations permanently cashless.

We hope for similar successes as we keep sharing people's insights about the need for 'offline' options. This includes ways for people to keep their homes warm, and many other areas.

# In your area



## Ultra heroes

A team from Torfaen, south Wales has raised almost £6,000 for Alzheimer's Society by running an incredible 100km in one day.

Lloyd Bartley took on the Cotswold Way Challenge ultramarathon at the end of June with his brother Rhys and friends Richard Appleby, Gareth Rusby-Davies, David Jenkins, Richard Darch and Tom Sterling.

Lloyd said, 'We chose this charity as my dad has early-onset dementia. He's 66 – not an age many of us associate with dementia.'

'My dad's dementia has had a big impact on my family. My mum is now my dad's full-time carer and has to help him with every aspect of his day-to-day life.'

Although completing the ultramarathon was hard, it was more than worth it at the end.

'We all managed to finish the challenge,' said Lloyd. 'There were quite a few injuries along the way, with some of us suffering more than others.'

'My parents were at the finish line to see my brother and I finish, which was amazing. It was a massive sense of achievement.'



## Honouring mum

A supporter in Coleraine, Northern Ireland, has raised over £2,000 for the Society in memory of her mum, who had Alzheimer's and died aged 74 last year.

For Cathy McColgan, Cupcake Day in June wasn't only a way to raise funds. It was also a way to bring family and friends together to honour her mum Sally, whose funeral had been restricted due to coronavirus.

Cathy said, 'Mummy brought four of us up singlehandedly since I was maybe nine years old. She went without to make sure we had what we needed.'

Cathy invited a close group of friends and family to come to the fundraiser and it was the first time she had seen many of them since her mum died.

'It was great to see people again and they were so generous. I set up a one-way system so people came in the front door and out the back, and it was all socially distanced with masks and sanitiser.'

'We had cupcakes, gluten free cupcakes, fruitcake, Victoria sponge, mince pies that were all homemade and then people donated shop bought stuff too.'

For fundraising ideas throughout the year, see [alzheimer.org.uk/fundraise](https://alzheimer.org.uk/fundraise) or call **0330 333 0804**.



Photograph: Museum of London

## Culture for all

London has established the world's first Dementia Friendly Venues Charter, with over 40 major theatres, museums and other venues already on board.

Venues will make themselves more accessible to people affected by dementia through sensory tours, inclusive performances, relaxed sessions, clear signage, chill out zones and staff training.

Organisations signed up to the charter also join a Dementia Friendly Arts and Culture Network, hosted by the Museum of London, that will share best practice and help staff and volunteers become Dementia Friends. Alzheimer's Society will give them further support to become more dementia friendly.

Sadiq Khan, Mayor of London, said, 'As our city begins to reopen and our campaign to attract visitors gets into full swing, I want to send a clear message that our cultural venues are here to welcome people with dementia and we all have a part to play to ensure our capital is a more welcoming place.'

Kate Lee, our CEO, added, 'Venues like the Museum of London are leading the way, and we'd like to thank them, the Mayor of London and City Hall for their continued dedication towards making London the world's first dementia-friendly capital city.'



## Zoe Campbell, Director of Operations

### Why dementia, why the Society?

I worked in adult social care for several years and was really shocked to see that dementia was often not recorded as a reason for providing support. That meant the risk of under-resourcing dementia was real and large.

I also found that dementia is not acknowledged as a health condition but as a social care matter, which can cause huge barriers to peoples' ability to access financial and other support.

When I saw a role advertised at Alzheimer's Society, I knew I had to go for it. It presented an opportunity to take my prior learning and knowledge and to use it in a way that could create real, positive change.

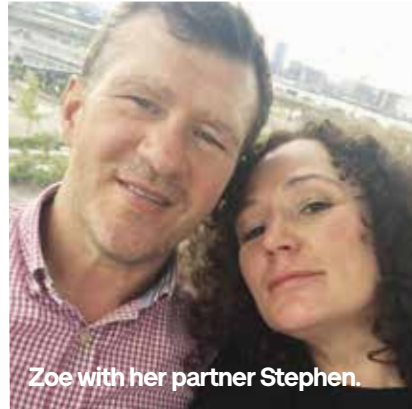
### How to fill an unexpected day off?

Stephen and I would head up to Bamburgh. I'd enjoy a Guinness in the Victoria Hotel then lose myself walking on the wide, open, sandy beaches, staring at the horizon and admiring what is my favourite Northumberland castle.

### Proudest achievement?

I learned to ride a bike about two weeks ago – that made me very proud! Also getting a degree in three years through the Open University while working full time and being a single parent to two children.

I would also throw in those two children, they make me immensely proud. My son has dyspraxia and dyslexia but got a law degree and my daughter took it upon herself to move to Australia, travel around Japan and now lives in New Zealand.



Zoe with her partner Stephen.

### Worst advice you've been given?

Someone once advised me to consider elocution lessons, as I wouldn't get on in life with a Geordie accent. I did not take the advice and every time I saw them after that I amplified my accent – I mean, tell Ant and Dec that!

### Biggest priority for coming months?

Making sure we provide the best possible support we can for people affected by dementia, which includes making sure the Society is a great place to work and volunteer.

### Most important thing learned from a person with dementia?

This one is really tricky, there are so many I could draw upon. Given that, I am going to say that the most important thing has been: everyone who has dementia has a unique, individual experience and is a unique individual.

### Most looking forward to?

The ability to be a bit more spontaneous – not having to book tables and having to remember to take your mask before you can go anywhere.

# Take courage

Pranab Das has been trying to navigate the challenges of dementia care since his wife's diagnosis. **Gareth Bracken** speaks to a husband who will never stop showing love.



## Quick read

Pranab Das has been trying to navigate the challenges of dementia care since his wife Lucie's mixed dementia diagnosis in 2019.

Pranab, in the West Midlands, says he's constantly learning, and praises the support he's had from Alzheimer's Society.

He's had bad experiences with both social services and homecare agencies.

Pranab hopes that his story will inspire others caring for a relative with dementia to take courage and continue showing their love.



**‘For me, every day is a new day – it’s continuous learning,’ says Pranab Das, whose wife, Lucie, has mixed dementia.**

Supporting Lucie has been a ‘big education’ for Pranab. He wants her to be able to remain at home, but has faced challenges trying to find the right professional care.

Despite all of this, and his worries about the future, Pranab strives to always be there for his wife.

‘I do wonder, what is going to happen? Where is this going to lead? It’s very sad and sometimes I cry,’ he says.

‘Luckily, one thing remains constant – the warmth of her, our mutual warmth.’

### **Romeo and Juliet**

Pranab is a biochemist who was born in India before coming to England in 1963 to further his research career. He recalls arriving in France during a cold winter, following a ‘remarkable’ two-week boat trip, before getting the renowned Golden Arrow train non-stop to London.

Pranab studied genetics and enzymes, and how plants can be used to treat disease. He was also a lecturer in many places, including Hong Kong and Amsterdam, and remains an Honorary Senior Research and Teaching Fellow at the University of Birmingham.

Lucie is French and was born in Tunisia in north Africa, when it was a French colony. The couple, both now 80, have been married for 54 years, having met in London in 1967. They have one daughter, Elsa, a GP in France.

‘Lucie was an exceptional woman’, says Pranab, who lives in Sutton Coldfield in the West Midlands.

‘My daughter says we’re like a Romeo and Juliet – we’re

inseparable. When we were both in our 70s, we went to Beijing for a conference and they gave us the honeymoon suite because they thought we were newlyweds!

‘Lucie was a daydreamer but also incredibly well read in literature. She was interested in



psychoanalysis and wrote a book about the dreams she had and what they meant. We were in the process of publishing it when she got sick.’

### **Why her?**

Looking back, Pranab wonders if Lucie’s ‘dreamy’ persona meant that he didn’t notice her dementia symptoms sooner. His earliest recollection is a 2018

trip to Brazil, around which time Lucie was experiencing changes in her physical and mental health, including headaches, flu-like symptoms and what Pranab describes as ‘depressive’ behaviour.

Back in England, she was given antidepressants and later hospitalised. She was moved to a psychiatric unit but lost weight and had a heart attack. A brain scan suggested vascular dementia, before an official diagnosis of mixed dementia in July 2019.

‘I started with despair: “Why her?”’ says Pranab. ‘She was a late bloomer who had started enjoying life in her own way. She was volunteering in a hospice bookshop and was going to publish her own book, and then suddenly dementia.’

‘I felt sad and scared. “How am I going to go through it?”’

### **Quality care**

Lucie can become agitated with Pranab, swearing at him in different languages. She also has fragmented sleep and experiences confusion, for example thinking that something she has read in a book is real life.

‘Sometimes she thinks that she’s caring for me,’ says Pranab. ‘Lucie is a bit incontinent but she’ll tell me to wear my nappies – she’ll say I’ve got dementia.’

‘I’m a medical scientist but you can’t explain dementia scientifically, it’s a mystifying disease.’

Pranab had a bad experience with what he describes as ‘laughable’ support from social services, before arranging care at home from agencies. He’s very critical of many of these too.

‘Some carers are so good and are well connected with my wife and I, and then their agency changes the person and the whole process goes down the drain,’ he

says. 'These relationships are so important, but the managers don't seem to want to build them.

'Care agencies boast about their dementia expertise, but no one is an expert.'

Pranab, who made an official complaint against one agency, feels that making money can come before providing a good service.

'I had to pay for the care unless it's cancelled 12 hours before, but Lucie isn't always in the right mood for a carer to visit. I can't predict 12 hours in advance with a person with dementia.'

### **Like a daughter**

Pranab was referred to Alzheimer's Society by a social worker, and has received excellent support from Kiran Daman, a Dementia Support Worker.

'Kiran is tremendous,' says Pranab. 'She's almost like a daughter to me. If I don't hear from her, I get nervous!'

Kiran advises Pranab on how best to support both Lucie and himself.

'Lucie used to be aggressive and was spitting at me, but Kiran told me how to handle it,' says Pranab. 'She said to leave the room and come back as if nothing happened. And she was right.'

'Kiran has also taught me to be patient. I'm an ill-tempered person, agitated very easily. She helped me to become tolerant and calm.'

Meanwhile the pandemic has created new challenges for Pranab who, along with Lucie, had his second COVID vaccination in April.

'The pandemic has made everything worse,' he says. 'My daughter used to visit once a month from Paris, but now I have her and my granddaughter Mila on the phone trying to get Lucie to eat.'

“  
**People with  
dementia are  
not completely  
obscured.  
They still have  
creativity, it's  
just all mixed up.  
They can still feel  
your warmth, so  
don't ever stop  
giving them love.**  
”

### **Don't stop**

As he continues doing all he can to ensure that Lucie receives the best possible care and support, Pranab hopes his story will inspire others to keep going.

'I never dreamt this would happen. I'm still on the journey and every day is a new experience,' he says. 'You face the despair, but you have to be courageous.'

'People with dementia are not completely obscured. They still have creativity, it's just all mixed up. They can still feel your warmth, so don't ever stop giving them love.'







For Caring for a person with dementia:  
A practical guide, go to [alzheimers.org.uk/carersguide](http://alzheimers.org.uk/carersguide)  
or call 0300 303 5933.

Stand up for all people affected by dementia  
by joining our campaign at [alzheimers.org.uk/campaign](http://alzheimers.org.uk/campaign)



### **What can you do to help?**

You can help ensure that more carers like Pranab receive the support that they need. Please **give what you can today.**

# Talk about tomorrow

Conversations about end of life care for a person with dementia can be difficult. **Gareth Bracken** hears how people living with the condition are encouraging dialogue.

## Quick read

Planning ahead for end of life care is an important but also emotive area for people with dementia.

Recent webinars from the 3 Nations Dementia Working Group saw people affected by dementia share their views on the topic.

Advance care planning is where a person records their preferences for any future treatment and care, which can be updated later.

Alzheimer's Society worked with people affected by dementia to produce a resource to support conversations about a person's future wishes.

**T**he focus has been on living well with dementia, and quite rightly so. But we do need to focus on the other side of the coin, and dying well with dementia is a very important part of that.'

Those were the words of Keith Oliver – an Alzheimer's Society Ambassador who lives with dementia – during a recent discussion about planning for the end of life.

These sorts of conversations can be difficult for anyone, and especially for a person with dementia who may not want to dwell on how their condition will progress. However, there are also benefits to having a plan in place, such as the peace of mind that comes from knowing that your wishes and preferences are recorded and will be respected.

### Dying well

The 3 Nations Dementia Working Group (3NDWG) is made up of people with dementia who use their lived experience to improve the lives of those affected by the condition. The 3NDWG is led by a

steering group and has members across Wales, Northern Ireland and England.

Throughout the pandemic the 3NDWG has been hosting a series of dementia webinars, including two themed Living Well/Dying Well. These featured people affected by dementia and professionals talking about advance care planning and end of life.

Nigel Hullah, who like Keith is a steering group member who contributed to the webinars, was among those keen to address this important but emotive issue.

'We don't have conversations about end of life, so I wanted to start one nationally about the way people wish to leave this life,' he says.

'But we had to get the timing right, as I'd have felt uncomfortable doing it when the pandemic was claiming lives left, right and centre.

'I thought the webinars were great. It was the genuine voices of people with dementia and carers.'

### Pain free

Speaking on one of the webinars was Jennifer Bute, who 'had the



privilege to walk the path with many during their living well and their dying well' in the 25 years she was a GP.

Jennifer, who has dementia, underlined the importance of people having a say in their future.

'I'm aware of the many assumptions that are made about dying well,' she said. 'Sadly, often relatives put their own wishes first or don't even bother to ask people what they might want.'

'The biggest challenge to me is enabling every person with dementia to have the opportunity to speak.'

Julie Hayden, who also has dementia, shared what would represent a 'good death' for her.

'The main focus of my end of life care is that it be as pain free as possible – comfort is key,' she said. 'I don't wish my life to be extended just because doctors can keep me breathing.'

'For me, life is about quality rather than quantity. And quality of life should be a self-determined factor, not to be assessed and decided upon by medics or well-meaning family.'

## Difficult subject

Nigel discussed advance care planning, where a person records their preferences for any future treatment and care. These can be taken into account when someone's no longer able to make decisions about their own care.

'Advance care planning can happen at the most appropriate time for the person and provides a map of how you wish to be treated at the end of your life,' he said. 'The important thing to remember is that it's not a final document, because people's preferences change.'

'Planning for your death is part of the wellbeing process and people feel better for it, even though it's a very difficult subject.'

## Future wishes

Working with West Yorkshire and Harrogate Health and Care Partnership, Alzheimer's Society has created a free resource to make advance care planning a bit easier to approach.

The My Future Wishes – Conversation starter pack can help discussions about things like

lasting powers of attorney (LPAs), medical decisions and preferences for care. Although the information about LPAs is specific to England and Wales, most of the rest of the pack is relevant to anyone in the UK.

Developed in partnership with people affected by dementia, the pack includes tips for discussing tricky topics alongside advice about how to have your wishes recorded and registered.

'The pack is designed to break up this unapproachable term of "advance care planning" into manageable, understandable, bitesize chunks,' says Bindi Dhesi, a Dementia Voice Lead at the Society.

'If these conversations aren't being had or even suggested, then people's choices and wishes aren't known or recorded.'

'Then, when a crisis comes along, decisions are usually made in haste – potentially by health and social care professionals, and more than likely during a time of high stress. This isn't right and it certainly isn't fair, so we want to get people thinking and talking about their wishes.'

For our Planning ahead (1510) booklet and form, see [alzheimers.org.uk/publications](http://alzheimers.org.uk/publications) or call 0300 303 5933.

For more about the 3 Nations Dementia Working Group, see [www.3ndwg.org](http://www.3ndwg.org)

To download My Future Wishes – Conversation starter pack, visit [www.bit.ly/acpdementia](http://www.bit.ly/acpdementia)



# Better sleep

Disturbed nights can be hugely challenging for people affected by dementia. **Gareth Bracken** reports on a sleep study that's aiming to improve quality of life.

## Quick read

A research study called DREAMS:START hopes to help carers better support relatives with dementia who have disturbed sleep.

The approach involves a healthcare practitioner working with people affected to develop helpful ideas that suit them.

The study is supported by our Research Network, whose volunteers have helped shape many aspects, including language and recruitment.

If DREAMS:START helps, researchers will look to make its successful elements more widely available as soon as possible.

**M**any people living with dementia have disturbed sleep. This can include sleeping less and walking about at night, and feeling excessively sleepy during the day. Family members woken up by this may become exhausted and stressed. Costs to get extra care overnight can be unaffordable, and so it might not be possible for the person to continue being supported at home.

A study called DREAMS:START (Dementia Related Manual for Sleep: Strategies for Relatives) hopes to help carers manage a person's disturbed sleep better.

'There are currently no known effective, safe treatments for sleep problems in people with dementia, possibly because there may be many causes even in the same person,' says Penny

Rapaport, Co-chief Investigator on DREAMS:START and a clinical psychologist at UCL in London.

## Big difference

Through DREAMS:START, healthcare workers with a psychology degree hold six sessions with a carer, discussing how to improve the sleep of the person with dementia, who can also join the conversation.

The ideas are flexible, based on evidence and what works for participants, and can involve light, activity, comfort, routine and relaxation.

A small study was done first to see whether DREAMS:START would be feasible. Around two-thirds of people approached agreed to participate in this, about 90% of them finished the six sessions and feedback was generally positive.



Anna-Louise Smith



Jane Ward



Penny Rapaport

For our Understanding sleep problems, night-time disturbance and dementia (534) factsheet, go to [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) or call 0300 303 5933.

‘It was really enlightening,’ said one daughter. ‘There were things that I would overlook that I didn’t realise were that important.’

Another daughter, who lives with her mum, said the programme worked really well for both of them.

‘Even people at work noticed a difference with me, because I was sleeping at night,’ she said.

### Nothing worse

The main DREAMS:START study will see whether people with dementia living at home are sleeping better eight months after the sessions – and whether this improves their quality of life.

Researchers are recruiting 370 family carers in England whose relatives have sleep difficulties for a randomised trial. This means that a computer will decide who has DREAMS:START sessions and who only has more usual support.

One participant already recruited is Jane Güleç, who lives near York and whose aunt has dementia.

‘My aunt is continually up and down in the night,’ says Jane. ‘On a bad night she can be wandering up and down the stairs, wondering where people are, or getting dressed and undressed. Sometimes she goes to bed already anticipating a bad night.’

‘There’s nothing worse than continually disrupted sleep for getting you down – it makes it much harder.’

‘Anything I can do that might help my aunt, myself and people in the future is worth trying.’

### Unique insight

DREAMS:START is funded by the National Institute for Health Research and supported by our Research Network. Network volunteers use their personal experiences of dementia to influence dementia research.

‘Members offer a unique insight which motivates researchers and helps them to understand the priorities of people affected by dementia,’ says Anna-Louise Smith, Research Engagement Manager at the Society.

Rossana Horsley is a Research Network volunteer who cared for her mother with dementia for three years.

‘Sleep was a major issue. She would get up at night distressed and it was hard to calm her down, so my sleep was completely savaged,’ says Rossana.

‘The research really spoke to me, so I wanted to help if I could.’

Rossana has supported DREAMS:START in many ways since it began in 2015. This includes helping to shape the feasibility study and ensuring that resources – such as the manual used in sessions – are as user-friendly as possible.

‘Sometimes research can be a bit technical, so I’m very much

presenting a lay person’s perspective,’ she says. ‘I’m helping to refine things and put them into more accessible language. It feels my contribution is worthwhile.’

### Get involved

Another Research Network volunteer, Jane Ward, is a carer of eight years who continues to experience issues with sleep. Her involvement in DREAMS:START has included advising on the recruitment of people to take part.

‘We’ve discussed how to promote the study to groups who may not normally hear about research,’ she says. ‘We’ve also talked a lot about how people often don’t understand that research isn’t just about sticking needles into people, especially after all of the coverage of the COVID vaccination programme.’

‘We need to get word out there that there are a lot of other ways that people can get involved.’

If DREAMS:START works, researchers will look to make its successful elements more widely available as soon as possible.

‘It will mean that services can offer an effective treatment to improve the lives of people with dementia and their families,’ says Penny.

To find out more about taking part in this study, email Trial Manager Sarah Amador on [s.amador@ucl.ac.uk](mailto:s.amador@ucl.ac.uk)

Visit [alzheimers.org.uk/researchnetwork](https://alzheimers.org.uk/researchnetwork) or call **020 7423 3563** to find out more about our Research Network.



### What can you do to help?

You can help fund vital research to improve the lives of people with dementia, now and in the future. Please **give what you can today**.

Your letters, emails, social media posts and messages on our online community.

## Priority service registers

### Letter of the month

I was given a past copy of Dementia together magazine at a memory café and spotted a small paragraph promoting the priority service registers kept by water, gas and electricity providers.

I would strongly encourage people to register if they have health problems of any sort or are simply older. Although I cannot speak for gas, water or electrical distribution network operators (DNOs) other than Western Power Distribution, I have been a member of their customer panel for a long time and can assure you that they will look after you very well indeed.

The service is willingly and cheerfully given. Indeed, Western Power Distribution will offer advice and put you in contact with the appropriate people even for problems beyond loss of power. Once on their priority service register, people will be warned of potential losses and asked if they will need help. If they are critically dependent on electricity, a generator will appear within hours of a loss. For long outages, further help will be made available including hot meals via the Red Cross. Their staff are very well trained indeed and know how to approach someone with dementia. If you look at their control centre displays at house level, the houses of people with dementia are marked with a red heart!

To avoid any confusion, the DNO owns and operates the public electrical distribution network – all the poles, wires, underground

cables, substations etc right up to your house switchboard. You never pay the DNO directly – they charge the electricity supplier, who you pay.

The DNOs are trying to ensure that they have a common register with the gas and water people, although this is complicated by supply areas being different as well as by current data protection regulations. You will never be approached for commercial purposes when you are on the priority service register, although you will be phoned every two years or so to check that you still need to be on the register and that you are still present.

**Michael Rowe, Somerset**

**Congratulations to our letter of the month writer, who will receive a bouquet of flowers.**

**People affected by dementia can register to get extra support in case something goes wrong with energy or water supplies, or if they need help with using appliances safely.**

**The type of extra support depends on where you are – contact your electricity, gas and water companies (the people who bill you) and ask about their priority service register. In Northern Ireland, these are sometimes called customer care schemes.**



### Your turn

Tell us what you think – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk)

Letters for the October/ November issue to arrive by end of 5 September. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

## Poetry competition 2021

We were blown away by the 220 poems sent into our competition from 141 poets – thank you all for sharing your wonderful work with us!

Our special panel of people affected by dementia and poets is looking at all the entries to agree two shortlists – poems written 'From the heart' and showing 'A way with words' – and poet Vahni Capildeo, our guest judge, will select the winners from these.

Look out for the October/ November magazine, where we'll announce the winners and publish their winning poems.

In the meantime, do continue to share your poems about dementia on social media and in the Members' Area of our online community Talking Point – visit [alzheimers.org.uk/talkingpoint](https://alzheimers.org.uk/talkingpoint)



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## Seen elsewhere...



After we shared a post on Facebook about delivering our Cure the Care System petition to the Prime Minister, Karen Markus responded:

“All carers need help. The only ones who know how tough it is are fellow carers and we deserve so much more recognition and help from those in authority. In these difficult times – to all – I say WE can do this and keep going.”



On Twitter, Dementia Friendly Middlesbrough shared a picture of the latest Dementia Friends at a local community hub in Redcar:

“Great group of people from Tees Community Hub @CommunityTees all became Dementia Friends – all learnt more about living with dementia @HwRedcarCleveland @RedcarCollege @DementiaFriends #dementia”



On Talking Point, our online community, Dimpsy was thankful after sharing how they felt about having to make difficult decisions over their mother's care as her dementia progresses:

“It's such a relief to start writing a thread about Mum, there's no one else I can talk to apart from my cousin, whose father was put straight into care when he showed signs of dementia. This forum has helped with so many hurdles we've had to jump so far.”

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## Take part in research

Are you feeling inspired by NIDUS-family (p15) and DREAMS:START (p28)? More opportunities to take part in research include:

- The DACHA study, led by the University of Hertfordshire, is asking relatives of care home residents what information the home currently gives them, and how this compares to the information they'd like to get – visit [www.dachastudy.com](http://www.dachastudy.com)
- Kitty Clucas, at the University of Bristol, would like to speak to bisexual people with dementia about their experiences to help improve social care – email [ur19993@bristol.ac.uk](mailto:ur19993@bristol.ac.uk) or call 07854 389924.
- Jayne Astbury, at the University of Manchester, is learning how local authority support received by over-70s caring for a person with dementia at home changed over the pandemic – email [jayne.astbury@manchester.ac.uk](mailto:jayne.astbury@manchester.ac.uk) or call 07385 463137.

To find out what other studies you could take part in, see [www.joindementiaresearch.org.uk](http://www.joindementiaresearch.org.uk) or call 0333 150 3456 and ask about Join Dementia Research.

We test products designed to prompt conversation and reminiscence for people with dementia who have Caribbean or African heritage.

## Fitting memories

**W**hen Feyi Raimi-Abraham couldn't find reminiscence products that were culturally relevant for her mother, who grew up in Trinidad, she set up the Black Dementia Company. They produce puzzles and activity books with imagery and topics selected specially for people with African or Caribbean heritage.

These are now available through our online shop and – with the help of Anndeloris Chacon at Bristol Black Carers and Trish Caverly at Bristol Dementia Wellbeing Service – we sent a range of them out to be tested by people at home.

### Vintage images

There are seven 16-piece jigsaw puzzles, each with a vintage photo from a carefully chosen place and time – Trinidad 1960s, Nairobi 1960s, Shitta-Bey Mosque 1960, Caribbean 1963, Ewa, Lagos c.1950, Friends in Lagos c.1961 and Government Road, Nairobi 1957.

The people we contacted through Bristol Black Carers liked and identified with the packaging of all the products. They said it looked appealing while being clear about what's inside.

A carer said, 'The cover got my attention because it had Black people featured on it' – something specifically mentioned by one person with dementia too.

'Mum is enjoying the puzzles,' said another carer. 'We like the size of the puzzle, it's perfect.'

Many carers said the large jigsaw pieces were helpful, and a person with dementia commented, 'I find the puzzle pieces brilliant and easy to use.'

The puzzles all use photos that are either black and white or with limited colour, and this was also appreciated by our testers.

'The colours in black and white and it make things easier,' said a person living with dementia.

Although one carer said that helping their mother hold the pieces was straightforward, it was difficult to get her interest because she wasn't used to doing puzzles. However, they went down well with most of the people who tried them.

'My husband likes doing the puzzles and so does it as and when he got the time,' said one.

### Pictures and words

The Tropical Colouring Book and Tropical Colouring Book Volume 2 each contain over 30 pages with illustrations of flowers, people and more that resonate with African and Caribbean cultures. They also have blank areas that can be used to draw more pictures.

The Wordsearch and More Book includes puzzles with tropical-themed words to be found in them, as well as short quizzes.

Our Bristol Black Carers contacts thought the colouring book images were great. One person with dementia said, 'Because of the size, it was easier to stay in the lines and there are a

lot of different drawings.'

Another said, 'It brought back memories for me as a child doing the colouring.'

'I enjoyed working through the book,' said another of our testers, 'and the cover appealed to me.'

A carer said, 'It's nice seeing Black people in the pictures wearing headwraps, which are still relevant and trending with women and young people.'

One carer liked, 'seeing the flowers, parrot bird, drums, men playing the steel bands, clothing that is still relevant,' and another agreed, 'Afro hair, the person with the basket on her head, the men in the canoe – I visualise this through the eyes of my grandparents.'

The use of blank spaces was appreciated, with one carer saying, 'It helped my mother to focus on one drawing at a time.'

Brigitte in Gloucester felt certain that her husband wouldn't be interested in the idea of colouring in, even though the pictures would chime with his Caribbean heritage. Her solution was for them to spend an hour looking at the pictures and reminiscing about 'back home' – an idea that could be adopted by others.

'He named the fruit and together we remembered all the lovely fruits and foods on his island and how his mum used to make lovely fruit juices, and how she was the best cook ever and taught all her children to cook,' said Brigitte.

'The illustration of the hummingbird brought out a lovely conversation about the French name for the hummingbird, and the lady in the traditional dress reminded him of his mum, who was a seamstress, sewing dresses for the ladies back home.'

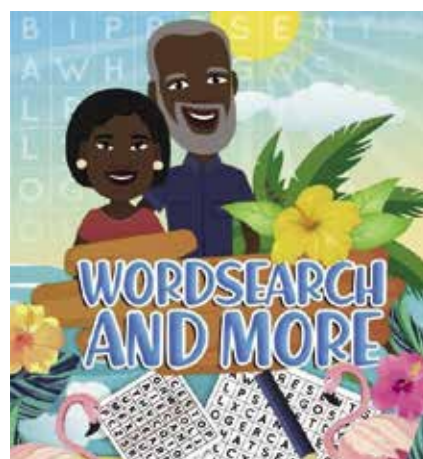
Of those who tried the wordsearches and quizzes, one said, 'I love everything about the book.'


'I think it is a great book for carer and cared-for,' said another.

Our Bristol Black Carers testers agreed that – although they hoped mass production might make them cheaper – all these products are good value. They said they would have bought them for themselves and would recommend them to other people.

The 16-piece jigsaw puzzles are £13.33 plus VAT each, and the Tropical Colouring Book, Tropical Colouring Book Volume 2 and Wordsearch and More Book are £10 plus VAT each, all from our online shop.

Visit [shop.alzheimers.org.uk](http://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.



 **Win puzzles**  
See p39 for a chance to win jigsaw puzzles from the Black Dementia Company.





**We read a guide for people supporting a relative or friend who has dementia, written by someone with personal experience.**

## Dementia essentials

**J**an Hall's *Dementia Essentials*, first published in 2013, has been revised and updated to include new research and advice. As Jan writes in its introduction, the book aims to 'act as a guide and support' for those caring for family member or friend with dementia.

'It covers much of a person's dementia journey,' says Tomas René in our Publishing team, 'beginning with the initial recognition of symptoms ("First Suspicions") through to a final chapter on care in the later stages of dementia, including care in a hospital or care home. In between, it looks at a range of useful practical, financial and emotional considerations.'

Ann Marie Bird, a reader in West Midland, says, 'This book is informative and I wish I'd had it before my father was diagnosed with dementia.'

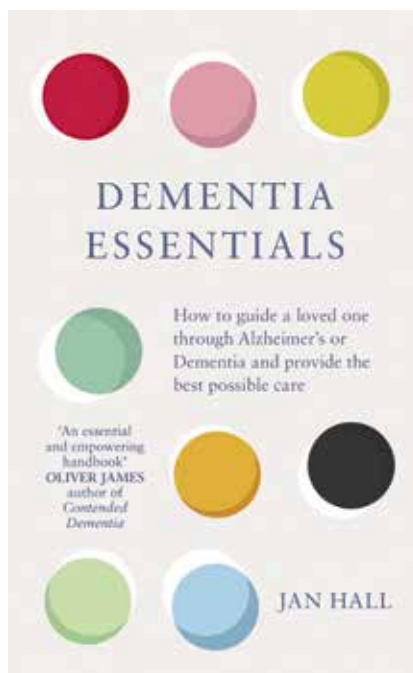
'It has lots of useful advice and contact information, and it's good to hear from others who are on the same journey so you know you're not alone.'

### Warm and personal

Anne Cowan in Rutland appreciated the book's content and style.

'It's good and easy reading,' she says, 'and covers most topics that I wanted information about.'

Tomas adds, 'What distinguishes this guide is its warm, informal tone and its focus on personal testimony. Jan herself helped care for her mother who had dementia and writes movingly about this. But she also weaves other first-hand accounts into the text throughout –



nearly every page includes a quote from someone who has been caring for a person with dementia.

'Including these personal accounts is also a recognition that everyone's experience of dementia will be different. Often, there is no right or wrong approach to a given situation, and in various contexts the book includes caveats such as "There is no 'one-size-fits-all' answer". By presenting lots of different people's voices, it offers several ideas and viewpoints.

'The book is further enriched by small philosophical moments, including a reflection on the importance of humour, and a passage from Jane Austen about the unpredictability of memory.'

### Always more

It wouldn't be possible to cover everything about dementia in a

single book, and the title of this one makes clear that it means to provide the 'essentials'.

However, Anne notes, 'I would have liked a little information about people with learning difficulties and dementia, but perhaps the ideas are the same.'

Tomas adds, 'As dementia is a life-shortening condition, some might feel the book would benefit from a concluding chapter on end of life care and death – these topics are broached only briefly earlier on.'

'Yet there is an eloquent section on the unique "living grief" that carers of people with dementia may experience. Jan writes compassionately about the feeling that, in the later stages of dementia, a person is "lost" twice – first to the condition and then again when they die.'

### Recommended

Key tips are highlighted at the beginning of each of the book's chapters and there are many links to organisations that could help further.

'In all, it's a useful and companionable guide,' says Tomas, 'ideal for picking up and putting down as needed.'

Ann Marie agrees, 'I would recommend it to anyone who would like to gain more knowledge and understanding on what they can do to support the person they love and care for.'

**Dementia essentials**  
(updated edition), by Jan Hall  
(Vermilion 2020), 272 pages,  
£12.99, ISBN: 9781785043413.



## Your turn

For the next issue, we invite you to read *Love and Care*, by Shaun Deeney (Endeavour 2021), 336 pages, £16.99, ISBN: 9781913068462. Tell us what you think about this memoir from a journalist caring for his mother. Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) by the end of 5 September so we can share it in our next issue.



## Book giveaway

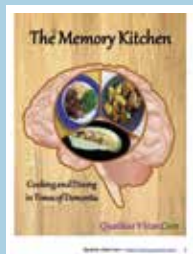
We have five copies of *Love and Care* to give away – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) by the end of 15 August quoting 'Care' for a chance to win one (see p39 for terms and conditions).

# Food and nutrition



### Eating and drinking factsheet

Our Eating and drinking (511) factsheet looks at ways dementia can affect eating and drinking, as well as tips to address the difficulties that a person with dementia may have. Visit [alzheimers.org.uk/publications](http://alzheimers.org.uk/publications) or call 0300 303 5933.



### The Memory Kitchen

An ebook from live-in care providers Qualitas Vitae Care features more than 70 illustrated recipes alongside helpful advice to deal with mealtime challenges. Buy for £9.75 from [www.memorykitchen.store](http://www.memorykitchen.store) in PDF, Kindle or epub formats.



### Making every drink count

Care UK, the care home provider, has produced a useful guide about hydration called Making every drink count. It includes tips on encouraging regular fluid intake and hydration from other sources. Visit [www.tinyurl.com/makeeverydrinkcount](http://www.tinyurl.com/makeeverydrinkcount) to download.



### Making Every Mouthful Count

A dietitian and former chef has published recipes and tips to support a person who is unintentionally losing weight, in paperback and Kindle formats – see [www.celiamannering.com](http://www.celiamannering.com). Making Every Mouthful Count: Recipes to help those with poor appetites gain weight, by Celia J Mannering (CreateSpace 2021), 158 pages, £14.99, ISBN: 9781717310965.



### End of life

A new booklet from charity Marie Curie provides information for family and friends about eating and drinking as dementia progresses towards the end of life. It covers strategies and tips, as well as where to get further support. To download, go to [www.tinyurl.com/mariecuriebooklet](http://www.tinyurl.com/mariecuriebooklet)

## Helpful products

Our online shop offers a range of products that can support eating and drinking as a person's dementia progresses, from Jelly Drops water sweets to specially designed cutlery and crockery. See [shop.alzheimers.org.uk](http://shop.alzheimers.org.uk) or call 0300 124 0900.



**‘My dad has dementia and he’s run up debts that he can’t pay off. What can we do?’**

## Dealing with debt

Anyone can get into debt, but managing money can become especially difficult as a person’s dementia progresses. They might buy things they don’t need because of memory problems or compulsive behaviour. They may also have extra bills – such as for care – and less money to pay them with.

### Does the debt still count?

Generally, people with dementia are responsible for debts they’ve run up, just like anyone else. This is true even if they go on to lose the ability (their ‘mental capacity’) to manage their own money.

If you can show that the person didn’t have this capacity when they got into debt – for example, at the time they paid for something – it might be possible to cancel what’s owed. You’d need to show that the seller knew, or should have known, that they lacked this capacity.

This can be hard to prove, but it’s worth discussing with the person who’s owed. If they don’t seem reasonable, you could make a complaint or take legal advice. You could also discuss this with a debt adviser.

### Managing existing debts

Specialist debt advisers can suggest ways to manage debt that you might not think of otherwise. The government’s MoneyHelper service can help you find a free and confidential adviser.

Breathing Space, a scheme for people struggling with debt in England and Wales, may help by freezing interest and fees until a longer term solution is found. MoneyHelper or a debt adviser can provide more details about this and other options, including in Northern Ireland.

### Stopping more debt

Talk to your dad – he might welcome some help with his finances. You could suggest that he ask his bank to put limits on his spending. He could set up a Lasting power of attorney to appoint someone to help him with his finances now or in the future, called an Enduring power of attorney in Northern Ireland.

If he doesn’t have mental capacity to do this, you or someone else may need to apply to become a deputy to look after his money on his behalf. In Northern Ireland this is called a controller.

If the bank believes your dad lacks capacity to manage his account, they may freeze it until his attorney, deputy or controller can take over.



### Further help

For MoneyHelper, go to [www.moneyhelper.org.uk](http://www.moneyhelper.org.uk) or call **0800 138 7777**.

Visit [alzheimers.org.uk/publications](http://alzheimers.org.uk/publications) or call **0300 303 5933** for the Managing your money (1501) booklet for people living with dementia.

See [www.lawsoc-ni.org](http://www.lawsoc-ni.org) or call **028 9023 1614** to find a solicitor in Northern Ireland, or visit [www.lawsociety.org.uk](http://www.lawsociety.org.uk) or call **020 7320 5650** to find one in England or Wales.

Could Sibstar help? Sibstar is a highly secure debit card and app to help people with dementia manage everyday spending, developed with support from Alzheimer’s Society. To find out more, visit [www.sibstar.co.uk](http://www.sibstar.co.uk)



Photograph: FreeImages.com/David Playford



## The great outdoors

Contact with nature can improve our wellbeing and help us feel less stressed. It also stimulates our senses, whether listening to birdsong, watching wildlife or feeling leaves.

Many people enjoy fresh air and the smell of grass. For some, the scent of herbs such as rosemary, mint and sage or flowers such as roses, lavender and jasmine are associated with meaningful memories.

Going for a walk or visiting a park can be great ways to spend time outdoors. Guidebooks and apps can help identify different types of plants, flowers and trees. Active Minds Nature Walkers and Nature Explorer packs (available from our online shop) contain prompts with objects and textures to look for.

Visit [www.wildlifetrusts.org](http://www.wildlifetrusts.org) or call **01636 677711** for information about nature reserves from the Wildlife Trusts. They also organise events, with opportunities to volunteer.

### Home and garden

Keen gardeners may enjoy mowing the lawn (yes, some people do!), watering plants, planting seeds, weeding or pruning. The Royal Horticultural Society has lots of information about garden plants and wildlife – see [www.rhs.org.uk](http://www.rhs.org.uk)

Even without a garden, you can plant a window box, take care of a house plant or grow herbs on a windowsill.

A birdfeeder could be placed so that someone can watch birds from a window. They might like looking at wildlife pictures in books or online. Themed colouring books and puzzles are available from our online shop, as are ‘Garden’ and ‘Seaside’ scent and CD sets – another way to evoke natural environments at home.

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

See our online shop for a range of helpful everyday products – go to [shop.alzheimers.org.uk](http://shop.alzheimers.org.uk) or call **0300 124 0900**.

### Over to you

Do you have any tips about enjoying nature that we could share next issue? Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) by 6 September.

## Wool crafts: What you said



Photograph: Oswald's Imaginarium

**Dee Tom**, on Talking Point, says, ‘Mum was an experienced knitter but now only manages scarves. There are a lot of holes these days and she gets cross when she realises they are there. We have a method to “celebrate” them – either with a contrasting colour of wool or, sometimes, a piece of thin ribbon, we create a little bow which closes up the hole and adds character. We love it!’

**Helly68** says, ‘Eventually Mummy enjoyed watching me sew, and seeing the results when she was no longer able to sew or knit herself. I also make braid using the historical version of a dolly bobbin, which some may remember from childhood. Techniques like this, and darning, can be of interest as a memory of something they did, which has largely fallen out of fashion. It can spark reminiscence.’



## Talking Point members' advice to someone who's struggling to be the 'perfect carer'.

# The 'perfect carer'

'There is no such thing as the perfect carer so don't give yourself a guilt driven depression trying to be something that doesn't exist. Unrealistic expectations drive us towards failure.'

'Always be prepared to say to everyone that you struggle and need help as you will be left to your own devices if everyone thinks that nothing is needed.'

**karaokePete**

'Pick your battles. Don't sweat the small stuff.'

**Jessbow**

'Show me a perfect carer, and I'll show you a liar. For the first couple of years if anyone asked how I was, I would shrug and say, "Oh it's fine, I manage." Trying to be a cross between a martyr or a saint.'

'The next couple of years broke me, and I'll tell anyone now how awful it is. People need to know, or else things will never change.'

**Thethirdmrsc**

'Deal with the here and now because the tomorrows will not be what you expect, so why worry.'

'If you need to do something, do it now. Tomorrow the \*\*\*\* might hit the fan and I mean that quite literally.'

'And the hardest one of all, ditch the guilt. You don't need it, it does no good and whatever you decide to do it will still be there. So wave it goodbye.'

**Catastrophe**

'Set yourself some limits and stick to them. Like how long you are going to care for and how you are to manage it. Caring is all about managing.'

'But also remember you have to take care of yourself. Remember, there is only one you. When it gets too bad for you is usually the time to step outside the box and "look" at yourself and the situation.'

**TNJJ**

'We each have different pressures and priorities in our lives. What I do and am willing to give up or not, may be different than my siblings choose. That doesn't make any of us better or worse than the others.'

**Terz**

'Please don't struggle, the caring is struggle enough without trying for perfection which looks different to each person who is caring.'

**superbat**

'Take a few minutes every now and then to look in the mirror and give yourself a pat on the back, be proud of how you're trying to do your best even though times are tough, forgive yourself for any times you've been impatient, and remind yourself just how special carers are.'

**mickeyplum**

'I just aim to be "good enough"!'

**fromnz123**

'I reckon the perfect carer does not exist, but someone could be getting close to it if they care for themselves as much as they care for the person they are caring for.'

**karty**

Visit [alzheimers.org.uk/talkingpoint](https://alzheimers.org.uk/talkingpoint) to read more and join our online community.



## Next issue

Do you have tips for supporting a person with dementia who's struggling to follow different rules and signs while out and about? Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) by the end of 5 September.

## Jigsaw puzzles

We have a Caribbean 1963 puzzle from the Black Dementia Company for one lucky winner and Friends in Lagos puzzle for a second drawn from correct entries received by 9 September, with Sister Grace cotton tea towels for five runners-up.

**Q: What is soursop?**

- A. A game.**
- B. A type of dress.**
- C. A fruit.**



**Send us your answers with your name and address**  
– email [magazine@alzheimers.org.uk](mailto: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.

## Book giveaway

See p35 for a chance to win a copy of *Love and Care*, by Shaun Deeney.



## Book giveaway

The five readers who each won a copy of the updated *Dementia Essentials*, by Jan Hall, were AM Bird in West Midland, T Jolley in South Yorkshire, C Donnison in Northumberland, P Skeete in Greater London and C Morgan in Gwynedd.

## Memory Walk T-shirt

We have Memory Walk T-shirts for three winners drawn from correct entries received by 2 September, and Memory Walk wristbands for five runners-up.



**Q: Memory Walk is:**

- A. Free to sign up for and open to everyone.**
- B. Only for readers of Dementia together magazine.**
- C. Only for people who can run a marathon in high heels.**

## Better together mug competition

J Millar in Cheshire, D Hawkins in South Yorkshire, A Cross in Orkney, A Redhead in Northumberland and G Mortimer in West Yorkshire each won a Better together mug. Answer: The English words 'tea' and 'coffee' came to the language from Dutch.

## Talking thermometer competition

T Jolley in South Yorkshire won an Ear and Forehead Talking Thermometer and S Thomas in Essex won a Non-contact Talking Thermometer, while P O'Leary in Greater London and A Redhead in Northumberland won pan pickle sets. Answer: A high temperature is usually considered to be 38°C or more.



# Who will you *walk* for?

Sign up today

Call: **0300 330 5452**

or search: **Memory Walk**

**Take part in Memory Walk this autumn and walk for a world without dementia.**

Join one of 20 events taking place across the UK or sign up to take on your own.

Who will you walk for?



Registered with  
**FUNDRAISING  
REGULATOR**

Alzheimer's Society is registered charity no. 296645



**Memory  
walk**

