



# Dementia together

## **Tough decisions**

The next stage of care

## **How can you take part?**

Join Dementia Research

## **Golden Memories**

Watford Football Club

## **Also in this issue**

Dementia Action Week

Clothes and shoes

Pension credit

# Being yourself

Hard-won positivity





# Welcome



**P**lease tell us what you think about the magazine by taking part in our readership survey before the end of May. We'd love to hear from as many of you as possible – if you didn't get your questionnaire with this issue, contact us using the details below or complete it online at [www.tinyurl.com/DTreaders](http://www.tinyurl.com/DTreaders)

This is the 124th issue of the Alzheimer's Society magazine, and the 25th called Dementia together. It looks completely different to when we combined two newsletters to launch a magazine back in 2007, and none of this change has been for change's sake.

We're continually finding new ways to make the magazine as interesting and relevant as it can be, based on what you tell us. Although we get useful feedback in various ways, this survey is vital for us to understand our readers and what you get from the magazine. Our last survey, five years ago, was immensely helpful and we expect to make excellent use of this year's findings too.

So, grab a cuppa and take a few minutes to complete and return your questionnaire – your opinions and ideas mean a great deal to us!

**Danny Ratnaik, Magazine Editor**



## Donate

**Text TOGETHER  
to 70660 to  
donate £3**

Text costs £3 plus network charge. Alzheimer's Society receives 100% of your donation.  
Obtain bill payer's permission.  
Customer care 0330 333 0804.  
Charity No. 296645.

**You can also donate online.**

## Need support? We're here for you – see p 18.

### Magazine contacts

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**, or write to us at **Magazine Editor, Alzheimer's Society, Scott Lodge, Scott Road, Plymouth PL2 3DU.**

Visit [alzheimers.org.uk/subscribe](http://alzheimers.org.uk/subscribe) or call **0330 333 0804** to receive each new magazine in the post.

Switch to the email version of the magazine at [alzheimers.org.uk/switch](http://alzheimers.org.uk/switch)

To get the magazine on audio CD or to update your subscription details, call **0330 333 0804** or email [enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)

See [alzheimers.org.uk/magazine](http://alzheimers.org.uk/magazine) for online articles, PDFs and podcasts.



**8** Andrea is full of hope.



**22** Nova and her mum.



**28** Football memories.

## News

Dementia Action Week **4**

## Being yourself

Hard-won positivity **8**

Fair play to that man **12**

Trusted experts **13**

Try something new **13**

A listening ear **14**

Meet the researcher:  
Barbara Sarkany **15**

How I enjoy the water **16**

Q&A: Swadesh Bala Jaitly **17**

Access for all **19**

In your area **20**

Spotlight: Chris Gottlieb **21**

## Tough decisions

The next stage of care **22**

## How can you take part?

Join Dementia Research **26**

## Golden Memories

Watford Football Club **28**

Letters **30**

Clothes and shoes **32**

What I Wish People Knew

About Dementia **34**

Pension credit **36**

Shopping for clothes **37**

A 'different person' **38**

Competitions **39**

## NI Assembly elections

If you're in Northern Ireland (NI), you can put key questions about dementia to candidates in the forthcoming NI Assembly elections.

Will they pledge to fully fund the rollout of the Regional Dementia Care Pathway – a vision for high quality dementia services? Will they make dementia a standalone priority in the reform of adult social care? And will they and their constituency office staff complete dementia friendly training? To email candidates, visit [alzheimers.org.uk/NI-campaigns](https://alzheimers.org.uk/NI-campaigns)

## Dementia Action Week 2022

This year's Dementia Action Week from 16–22 May will focus on getting a dementia diagnosis.

Dementia Action Week is the Society's biggest week of the year, when everyone connected with our work and the wider public rallies to improve the lives of people with dementia and their carers.

People affected by dementia will be at the heart of this year's campaign, which will encourage those who might be living with undiagnosed dementia to come to the Society for guidance and support.

Our Alzheimer's Society Annual Conference – covering key issues relating to diagnosis and support – is taking place during the week on 17 May, in London and with virtual places also available.

Visit [alzheimers.org.uk/DAW](https://alzheimers.org.uk/DAW) for more about the week, and book your conference place at [alzheimers.org.uk/conference](https://alzheimers.org.uk/conference)

## Local elections

Local elections will take place across Wales and in parts of England on 5 May. If this includes your area, ask candidates what they'll do to make sure people affected by dementia get the support they need.

We want candidates to commit to local councils having dementia strategies alongside an action plan. We're also calling for improved dementia diagnosis rates and waiting times, and we'll be following up with elected councillors. See [alzheimers.org.uk/campaign](https://alzheimers.org.uk/campaign)

## Forget Me Not Appeal

Our Forget Me Not Appeal this summer will ask people to show their support by wearing a Forget Me Not badge.

Wearing a badge in honour of someone special shows people affected by dementia that you understand and stand with them. Your badge is a symbol of solidarity and a message that they have not been forgotten.

By supporting the appeal, you're also funding life-changing support that people need right now. Who will you wear your badge for?

Visit [alzheimers.org.uk/forgetmenot](https://alzheimers.org.uk/forgetmenot) or call **0330 333 0804** to donate and get your badge.





## Directions

**W**ith so much anguish and strife in the world, it's tough to stay focused on what we can do to change things for the better. But I'm proud to say that, here at Team Alzheimer's, we've got your back.

There's so much that needs to be done to improve life for people affected by dementia, yet we're setting our sights on what will have the biggest and most meaningful impact.

We celebrated the House of Lords voting down an amendment that would have meant less affluent people having to pay a higher proportion of their assets on social care. However, we're still fighting for a fair cap on care costs as legislation progresses. The same goes for making sure people can visit loved ones in care homes safely – an issue that hasn't gone away despite life almost feeling like it's returning to normal for some.

Stretched services have created a backlog of people who need a dementia diagnosis, so there's no better time to shine a light on how important diagnosis is. That's what Dementia Action Week and our annual conference will do this May, so take part in any way you can.

As many people with dementia remind us, finding joy among all this is vital – and what better way than with cake and goodies! Join us with Bake for dementia this April... and to help burn off the excess, how about Trek26 this summer?

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



# Bake for dementia!

Cupcake Day has a new spin and will now be known as Bake for dementia! We think 2022 is the year for baking all types of goodies, so whether you're a whisk-taker, cake-faker or a baking pro, we'd love you to join us for Bake for dementia this April. Join in any day you like during the week of 25 April–1 May and bake (or fake) delicious treats to raise vital funds that will change lives.

Sign up for Bake for dementia at [alzheimers.org.uk/bakefordementia](https://alzheimers.org.uk/bakefordementia) or call 0300 222 5770.

---

## The same GP

Consistently seeing the same GP creates a good 'working relationship' between us and our doctor and we're less likely to face problems with how our medication is managed.

While this is believed to be the case for everyone, there was very little evidence about its specific benefits for people with dementia until Society-funded research led by João Correa Delgado at the University of Exeter.

João's team looked at the experiences of more than 9,000 people with dementia over a year. People who generally saw the same GP each time were less likely to experience delirium, incontinence and emergency hospitalisation when compared to people who'd seen different GPs.

They were also less likely to be taking inappropriate medications for any other medical conditions they had. For example, some drugs for high blood pressure can make incontinence worse. As incontinence is quite common for people with dementia, a drug that doesn't have this side effect is a better choice, but this might be missed by a GP who's less familiar with their patient.

Richard Oakley, our Associate Director of Research, said, 'The pandemic has put GP services under immense pressure, so while we might not be able to get consistent GP care for everyone with dementia tomorrow, policymakers should absolutely be working with the NHS to build this into their plans as we emerge from the pandemic.'

**For more about our dementia research see [alzheimers.org.uk/research](https://alzheimers.org.uk/research)**

---

---

## Join our board

We want Society volunteers to help set our strategic direction by joining our Board of Trustees. As our most senior governance group, the board makes sure the decisions we make enable us to support people in the most effective ways.

Trustees are appointed for three years on a voluntary basis, with a commitment of around two to three days a month. This includes quarterly meetings, examining and analysing performance and compliance reports, and helping to make strategy and financial decisions.

Two spaces become available in September, and we'll elect one replacement this year and one next year. To be nominated, you must be a registered volunteer who's been actively engaged with Society activities in the last 12 months.

Volunteers will be notified when nominations open, most likely around Easter time, with a ballot taking place in the summer.

---

## Singing on demand

Alzheimer's Society has partnered with My Life TV, an online on-demand streaming service described as 'like Netflix for people with dementia'.

Costing £3.99 a month after a free 30-day trial, My Life TV offers a wide range of programmes to help improve mood and wellbeing. Our popular Singing for the Brain sessions have been added for people to watch at any time. Visit [shop.alzheimers.org.uk/My-Life-TV](https://shop.alzheimers.org.uk/My-Life-TV) to start your My Life TV free trial.

---

---

## Diagnosis backlog

Alzheimer's Society is calling for significant investment to tackle the backlog in people with dementia getting a diagnosis due to the pandemic.

We estimate there are well over 30,000 people living with dementia in England alone who would have been diagnosed had the pandemic not happened. A timely diagnosis is essential to getting vital treatment, care and support, but only 61.6% of predicted dementia cases were diagnosed as of January, the lowest in five years.

James White, our Head of Public Affairs and Campaigns, said, 'We're calling for a clear recovery plan and investment of at least £70 million over the next two years, at the very minimum getting the dementia diagnosis rate back to the national target of 67%.'

There has also been a drastic drop in the number of people with dementia in England getting their care plans reviewed. These annual reviews by a GP are a key part of a person's care, but in the year to March 2021 the proportion receiving their review fell to 40%, down from 75% the previous year.

---

## Living with Dementia Toolkit

A new online resource uses videos, information and links to provide hope, inspiration and ideas for people with dementia and their carers. The Living with Dementia Toolkit was developed from the Society-funded IDEAL research programme, with the involvement of people affected by dementia. Please see [www.livingwithdementiatoolkit.org.uk](https://www.livingwithdementiatoolkit.org.uk)

---

---

## Deaf and dementia films

Alzheimer's Society Cymru has helped to produce four British Sign Language (BSL) films about dementia with members of the Deaf community.

A diagnosis of dementia for someone who is Deaf presents a unique set of challenges. Without the right information, understanding and support, they and their carer can become very isolated.

Created in collaboration with the British Deaf Association, with funding from the Welsh Government, the films increase awareness of dementia and how to recognise common symptoms. They tackle misunderstandings and offer tips on supporting a Deaf person with dementia. The films also provide advice on seeking an accurate diagnosis in a way that's linguistically and culturally adapted for BSL users. **Watch the Deaf and dementia films at [alzheimers.org.uk/bsl-factsheets](http://alzheimers.org.uk/bsl-factsheets)**

---

## Forward with Dementia

Forward with Dementia is a new personalised online guide to help people and professionals get the right information after a dementia diagnosis. It contains practical advice, personal experiences and news stories.

The guide was created as part of the international COGNISANCE study, the UK element of which is funded by Alzheimer's Society. See [www.forwardwithdementia.org/alz](http://www.forwardwithdementia.org/alz)

---

---

## New Dementia Voice groups

Join our new Dementia Voice groups and help make the work of Alzheimer's Society and other organisations more representative.

Through Dementia Voice, people affected by dementia share their thoughts and feedback on topics in many different ways.

The newest groups, which meet online every month, are for people from LGBTQ+, Deaf BSL and South Asian communities, and there's also one for younger people with dementia.

**To get involved with these and other Dementia Voice groups, visit [alzheimers.org.uk/dementiavoice](http://alzheimers.org.uk/dementiavoice)**

---

## Unforgettable football

Our charity partnership with The FA (Football Association) continues with a dedicated Alzheimer's Society international at Wembley Stadium.

England v Switzerland on 26 March plays host to numerous fundraising activities, as well as an awareness raising campaign across television, social media and at the stadium, with the strapline 'Football should be unforgettable'.

Our partnership with The FA hopes to raise over £500,000 to fund vital support services, help football become more dementia friendly and ensure that every fan knows they can turn to us for support. We'll also give guidance to The FA as it prioritises and funds research to protect players for generations to come.

**For more about our partnership with The FA, please visit [alzheimers.org.uk/fa](http://alzheimers.org.uk/fa)**

---

## What do you think?



**Take part in our readership survey before 31 May. It should only take around 10 minutes and your help will mean we can continue improving Dementia together magazine. Complete and return the questionnaire mailed with this issue, or do the online version at [www.tinyurl.com/DTreaders](http://www.tinyurl.com/DTreaders)**

## Don't miss...

Paul in Omagh, who has young-onset dementia, breeds parrots and hand-rears them from the egg. **See p12.**

John in Sunderland included the Society in his will because it was 'the obvious destination' for his money. **See p13.**

Swadesh in Surrey, who has Alzheimer's, says her family's support means she feels she's 'living again'. **See p17.**

Meet Kim, Senior Editor for accessible resources, and Chris, Director of Marketing and Communications. **See p19 and p21.**

Join Dementia Research helps people to take part in research that will change what it means to have the condition. **See p26.**

# Being yourself

Andrea Elliott-Denham brings hard-won positivity to life with dementia, after a long journey to be recognised as her true self. **Margaret Rooke** meets a woman full of hope.

## Quick read

Andrea Elliott-Denham, who is 67 and lives in Carmarthenshire, is focused on finding joy and hope since her Alzheimer's diagnosis.

Andrea and her partner Ella have valued the Society's advice and support, especially with their move to a less isolated area of Wales.

Andrea, who is trans, says her transition 20 years ago was the best thing that happened to her – besides meeting Ella.

She enjoys challenging herself with gardening and, although she doesn't read books anymore, is still learning from life.

**W**hen Andrea Elliott-Denham was told she had Alzheimer's, her main concern was for her partner, sitting by her side. Andrea could tell that Ella was overwhelmed by what she was hearing, struggling to take in the news and deal with what it would mean for their future.

Luckily, Andrea, now 67, was able to reassure her.

'I've been a carer in homes for the elderly and many of the residents had Alzheimer's, so the condition didn't frighten me,' she explains.

'I often worked nights, which meant I had more time to spend with everyone I was looking after, and they'd tell me about themselves. So I know what can happen with dementia and what doesn't always happen.'

Even so, Ella was in shock.

'When we saw the Alzheimer's nurse, I couldn't hear what he was saying,' recalls Ella. 'So he came here for an extra visit and that's when he told us about Alzheimer's Society.'

### Need to move

With few resources close at hand in rural Ceredigion, mid Wales, the couple could have been left feeling isolated and alone, especially during the COVID crisis.

Instead, Dementia Adviser Aranwen Turvey provided information and advice and stepped in to advocate for them when needed. Ella was still worried about how quickly Alzheimer's

would change their lives. Aranwen was the perfect person to put her mind at rest, and she did.

'It's so important we can speak to the same person each time,' says Andrea. 'We have someone who's easy to talk to, who knows us, so we don't have to tell our story from the beginning each time.'

The Society's help was particularly valuable when they realised how desperately they needed to move house.

'We used to live up in the mountains, with no neighbours and a 20-mile round trip to buy a pint of milk,' says Andrea.

'Ella doesn't drive and I had to stop driving because I was finding it too stressful. You'd think it would be peaceful in the country, but people here take blind bends so fast I couldn't deal with it.'

'We'd been waiting for a year for the council to move us, but Aranwen knew exactly how to deal with them in our situation. A couple of weeks after we asked for her help, we heard about this bungalow.'

They are thrilled with their move south, just across Ceredigion's border with Carmarthenshire.

'We have a shop literally round the corner,' says Ella, 'The girls at the shop know Andrea and that she has dementia, and they help her if I'm not with her.'

Aranwen is also helping them establish power of attorney for Ella for whenever it may be needed.



### **'Maybe tomorrow'**

The couple are settled in their new home, with their dog and cat, and a greenhouse built by Andrea's brother, who lives nearby, to encourage her love of nature.

This is a level of contentment Andrea didn't know in her early life, when she was brought up as 'Andrew'.

'I remember when I was three, I couldn't understand why I wasn't allowed to wear dresses like other girls. I'd ask my mum and she'd say, "Boys don't do that." I always felt I was in the wrong kind of body.'

She was bullied at school, and leaving at 14 was a relief.

'I went to work in a café on our local pier. After the summer holidays the others working there went back to school. I stayed on and ran the place for the rest of the year, but I never wanted to settle.

'I always had this feeling, "Maybe I'll wake up tomorrow and be the person I should have been."'

For many years, Andrea has also carried a deep personal tragedy. When she was 19, her eldest brother Nigel, who was two years older than her, died from carbon monoxide poisoning while in the bath of the flat they shared.

She spent so long comforting her mother that she hadn't focused on her own loss. Little support was available in those days.

Andrea found a succession of jobs, with stints as a carer, a canal attendant and working in the



House of Commons kitchen. She also ran her own antique shops.

Finally, 20 years ago, she had NHS support to transition and be recognised as Andrea.

'I felt, "At last I am that person." There was no more having to pretend. Such a relief. Besides meeting Ella, it was the best thing that happened.'

Both Andrea's mother and father were supportive, though trans matters were less widely understood then.

'I was quite surprised by my father's reaction. He had a brother who was gay, and he struggled to accept him, but if my mother ever called me "Andrew" by accident, my dad would say, "No, it's Andrea."'

Facebook groups have provided Andrea with a great deal of support and companionship. It was on one of these that Andrea met Ella, who she welcomed immediately.

'She was so friendly I thought she was the group moderator,' says

Ella, 'We started chatting and we kind of found each other.'

They have been inseparable since, and Andrea describes Ella as her 'rock'.

### Speaking out

Andrea started developing memory problems around six years later.

'I was forgetting names. Searching for a word felt like looking down a black hole.'

'Then one day we were in town chatting to someone. We had a good conversation and I turned to Ella afterwards and said, "Who is she?" It was someone I knew well, who had a shop next to mine.'

Andrea went to her GP and had a memory test, and later tests at hospital in Aberystwyth revealed Alzheimer's.

The diagnosis hasn't altered Andrea's vibrant personality.

'My colourful clothes reflect my personality – and no one can lose me!'

On a more serious note, Andrea is clear why it's important for her to speak out about Alzheimer's.

'One of the reasons is because I'm trans. I know there are people out there who have gone through what I've gone through, and they find it useful to read what I say.'

'We're all different but there are a lot of similarities as well. If I can make a difference in someone's life, that's important to me.'

'The other reason I speak out is that without Alzheimer's Society, life would be so much harder. They have been fantastic. We want to make sure people know this.'

### Learning from life

Andrea spends a lot of time posting in Facebook groups about what's happening in her life, most recently that her tastebuds have stopped working and that she sometimes hallucinates – symptoms she puts down to Alzheimer's.

'One of my brothers doesn't like me being trans but, besides him, people just accept me. I've never worried about reaching out for help or support.'

'I don't have a problem with who I am, and I don't expect others to. It's all about being yourself and not being afraid to ask people who understand you for help – help is out there. No one's going to judge who you are.'

'I'll be standing up at the bus stop and start talking to people and they give you their life story. Complete strangers!'

Andrea hopes that anyone providing her care in future respects her for who she is.



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

'I don't worry about the future, apart from how it may affect Ella. I've asked friends and family to give support to her if things get worse. She's my life.'

'I don't want to lose the memories of Ella and the times we've had together, our wonderful days living on a canal boat and walking in the mountains, but we don't get up in the morning and think "Alzheimer's" all the time. You can't obsess about it.'

Instead, she finds aspects of life that bring her joy.

'When I garden, I push the boundaries by growing tropical plants including bananas, vines and foxglove trees.'

'I don't read now, which is a shame because you learn a lot from books, but it's not the end. You learn a lot from life too.'



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

**Donate**

£20 could provide 34 dementia guides for people affected by a dementia diagnosis.  
Please, if you can, [donate online](#) today.

# Fair play to that man

Paul Monaghan in Omagh, aged 64 with young-onset dementia, encourages others to make their voices heard.



**I accepted my dementia diagnosis from the word go, there's no point moping. I have mild memory loss, and I know I'm not going to get better, but I'm on medication and everything seems to be going OK.**

I try to keep my brain as active as I can. I'm a keen parrot breeder, I hand-rear the babies from an egg. It gives you something to do every day, it gives you motivation. I also have brilliant family support, couldn't ask for any better.

## Worrying time

I go to fortnightly Zoom meetings through Dementia NI, where we're doing a children's app with universities. It asks different questions about dementia, to make them more aware of what's happening out there in the world.

At our monthly Alzheimer's Society meetings on Zoom, we've been talking about how the price of fuel and heating affects us. It's kind of a worrying time. The price of food is increasing, everything seems to be increasing, but people's money isn't going up!

I contributed to an Alzheimer's Society blog post about energy prices. My motto is that if you have anything to say, say it. If I think people are suffering because of the price of energy bills, I'll speak up.

People like us have a voice, and organisations like Dementia NI and Alzheimer's Society help us with that.

I keep in regular contact with my colleagues with dementia. We support each other. A wee call seems to cheer people up if they're down in the dumps.

Some groups are going back to face-to-face now. It's nice to see people's faces again and have a bit of a joke and a laugh. Although we're not out of the woods yet with COVID – you still have to protect yourself to the best of your ability.

## No shame

Dementia is nothing to be ashamed of – I didn't buy it! It's just been handed down to me, and I have to accept it. If you can't accept it, it's going to beat you.

I'm motivated to help people with the same result as me, who aren't as open or aren't accepting it. If I knew someone was getting diagnosed, I could be outside in the waiting room to tell them that it's not the end of the world. Or they could be given my contact number. I think that would be a good idea.

Everybody is equal in my eyes. It doesn't matter who you are or what job you have, everybody should be fit to use their voice and express their opinion. I want to make people aware that they have a voice.

I hope that someone reading this might think, 'Fair play to that man, maybe I should speak up more.'

Find out how you can use your experience of dementia to help shape our and others' work – visit [alzheimers.org.uk/dementiavoice](https://alzheimers.org.uk/dementiavoice)

# Trusted experts

**John Hartwright in Sunderland explains why the Society was the obvious choice for a legacy.**



**Both my parents had dementia at the time of their deaths. My dad was diagnosed with Huntington's disease and fairly quickly developed dementia. His behaviour became so disorientated that it really wasn't safe for him to be living at home, so he went into a nursing home and died in 2002.**

My mum had numerous stays in hospital – I have records of at least 25 admissions – with infections that often triggered delirium. This made diagnosis of her dementia more difficult, but we reached the stage where we had professional carers coming in four times a day to help me with taking care of her personal needs, until she died in early 2020.

### Here and now

I had no connection with Alzheimer's Society during the time my parents were alive. But after my mum's death, I was doing all the inevitable paperwork, and I thought I should update my will. I don't come from a large family and it just

seemed, given the experiences I've had, that Alzheimer's Society was the obvious destination that I would like the money to go to.

I think the Society struck me particularly because it's got this two-pronged approach. It's funding research, which is so important for the future, but also supporting people here and now who are going through dementia, and the people who are looking after them.

### Really important

I think it's really, really important that people have access to good, reliable, authoritative information, so that when things are happening to them and their loved ones, there's somewhere they can go to find out more about the situation they're in.

If you go to Amazon and type in 'dementia', you get books saying that they offer a cure for Alzheimer's. But there's no science behind it – it's giving people false hope. The Society is providing dependable facts, which is really important.

In the future I hope for better diagnosis, better treatment, a cure and maybe the ability to prevent dementia in the first place. I know that's going to be incredibly difficult, but I believe that one day it will happen.

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

## Work that brain



Keep your brain active with our monthly Brain Workout, delivered straight to your door. Enjoy word, number and logic puzzles while supporting people affected by dementia and funding vital research. Sign up with your choice of donation at [alzheimers.org.uk/brain-workout](https://www.alzheimers.org.uk/brain-workout) or call **0330 333 0804**.

## Pop open a pot



Jelly Drops – the bite-sized, sugar-free sweets with 95% water and added electrolytes to support hydration – are now available in handy pots of five sweets. Jelly Drop Snackpots come in packs of 21 in berry or citrus flavours, and cost from 95p per pot + shipping. Order as a one-off purchase or subscription at [www.jellydrops.com](https://www.jellydrops.com) or call **0808 164 8977**.

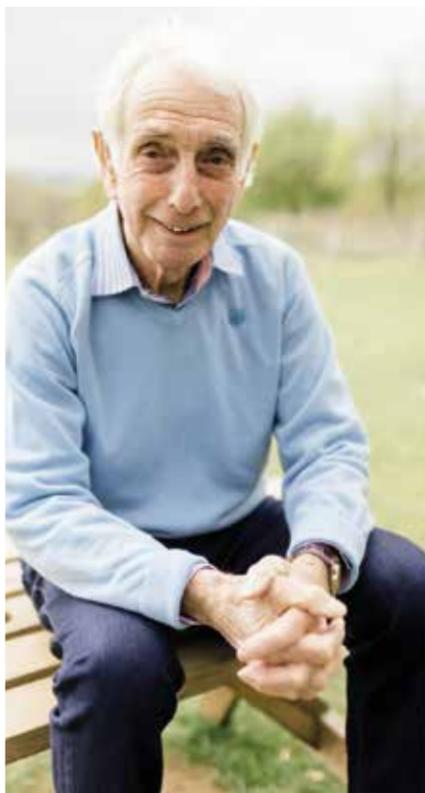
## Become a Dementia Friend

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://www.dementiafriends.org.uk) to get involved.



# A listening ear

As a Companion Call volunteer, **Brian Standing** in Somerset offers a listening ear to people affected by dementia.



**M**y journey as an Alzheimer's Society volunteer started in 2014, after a dear friend of mine had dementia.

I then became a Dementia Friends Champion and also volunteered to meet up regularly with people who would be isolated otherwise. In 2019 I was invited to join the Society's Volunteer Advisory Panel. I joined the new Companion Calls service in 2020, so I'm right on top of the action.

## Common ground

From day one, I had six clients who I now phone every week – four have dementia and two are carers.

The people I call are living alone, by and large, so we have common ground. I'm a senior and the people

I'm talking to are seniors, so I can relate to their younger years and the many events that were going on, like the coronation and rationing.

One of the first things I did was find out the places they live, their families and hobbies, and to build up a picture of their interests. One of them supports Arsenal, so I went online and found facts to share with him, and we have an ongoing discussion. One was an engineer in coal mining, so we talk about the miners' strike. Another guy and I both regularly put fruit in our porridge for breakfast – that's a discussion and a half!

With one lady, whose husband recently died, it's not uncommon for us to be on the phone for ages. We talk about all and everything – food, flowers, decorating, and the muntjac deer that lives in her front garden! I keep copious notes and use them to restart the conversation the following week.

## Adding support

I have been having conversations with a widow who lived in the Midlands for 30 years, and relocating was very stressful for her. That was an emotional journey we had together. I like to think it was supportive that I was around to have a chat.

You're not trying to find clever answers, but just be there, be a listening ear, so people don't feel quite so isolated. I'm just adding support by being at the end of the phone.

My clients also enjoy listening to what I've been doing – my hobbies include Nordic walking, and I collect

cactuses. We have a conversation that is two-way. I think that adds a bit more depth to the situation. It very quickly transpired that we were helping one another, and we've become good friends.

Find out more about becoming a Companion Calls volunteer – email [CompanionCalls@alzheimers.org.uk](mailto:CompanionCalls@alzheimers.org.uk) or call **0115 959 6176**.

# Meet the researcher: Barbara Sarkany

Doctoral student at the University of Oxford.



## Favourite things?

- Book – The Man Who Mistook His Wife for a Hat, by Oliver Sacks.
- Way to spend time – I love hiking and playing with my dog.
- Memory – When I tried out snorkelling as a child.

## Why dementia research?

I was always impressed by the complexity of the brain, it is an amazing and mysterious structure.

As with the whole human body, the brain can also develop pathological changes, and with ageing the risk of diseases of the brain increases.

This is becoming more apparent as the world's population ages – most of us can now expect to live well beyond our 60s. One of the

biggest consequences of ageing is dementia, which many of us know can cause great difficulties for patients and relatives, as well as the healthcare system.

My aim is to understand what happens to the brain over ageing and how it can be protected, to ultimately protect present and future generations of older people from the effects of diseases such as dementia.

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

I'm really grateful to Alzheimer's Society for providing me with a PhD scholarship. This scholarship gave me an amazing opportunity to understand the brain and dementia. Moreover, we have networking meetings with their volunteers and they provide precious feedback.

## What are you currently working on?

I investigate the role of the thalamus (a part of the brain) in Alzheimer's disease. Most studies focus on the role of the hippocampus (another part of the brain), but there are a few studies indicating that the thalamus plays a crucial role.

I assess the spread of a type of protein called tau in the human thalamus and its effects on activity of cells in the thalamus of mice.

## What difference do you hope this will make?

If we could gain a detailed picture of the spread of tau protein and its effect on brain cell activity, this might accelerate early diagnosis and drug development.

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

I would like to find out the possible causes of late-onset Alzheimer's. Importantly, ageing is the greatest risk factor for its development, but it is not well understood how gradual changes initially disrupt brain activity.

I hypothesise that proteins linked to the development of Alzheimer's – like tau – appear earlier in inner areas of the brain such as the thalamus, before spreading outwards. I'd like to understand the consequences of these proteins' accumulation on the activity of vulnerable brain cells, to see if there are clues about how to slow down or prevent the progression of Alzheimer's.

**Donate**

£6 could pay for 50 microscope slides – essential in spotting those tiny changes that happen in the brain with dementia.  
If you can, please [donate online today](#).

# How I enjoy the water

We ask people about how they keep well, whether they have dementia or not. This issue, we hear about swimming and enjoying the water.

## Rebecca Morris in Conwy



I like to go for a swim in the sea as often as possible. It allows my mind to wander and be free – once I've gotten used to the cold shock!

I try to go at least once a week. I try to go with my husband so he can keep an eye on me and our two dogs, although they rarely keep me company in the water.

I used to swim a lot as a child with seaside holidays. The water makes me happy and reminds me of family time.

The cold water sharpens my mind and keeps me focused. It also tires me out and gives me a good workout. It's also free!

## Nikki Willcock in Berkshire

Not swimming or being in water but being near water – sitting near the river and watching the boats, rowers and ducks. I try to go once per week with my father, and his carers do the same.

My father had sailing boats when he was younger in Devon and Cornwall. He fondly remembers

those days and sitting by the river evokes those memories. He can talk quite happily for ages about the days on the boats. Having a focus of attention brings back lovely memories.

## Karen Redparth in Surrey

I enjoy swimming weekly with my partner and child, and more often in the summer. I also like paddle boarding and being on the beach when holidaying. I've always loved swimming and anything to do with the water.

The benefits include fitness – which also helps with my asthma – making friends, being out in the fresh air, and feeling chilled away from life's stresses.

## Kristian Graham in County Down



I wasn't a regular swimmer, though when I was a lot younger I used to swim competitively. On a weekly basis, me and my son used to go to the pool, but I heard about Swim for Dementia and thought I'd give it a go.

I set my own target to swim 50km in one month – a couple of days in, I thought, 'What have I taken on here?' But seeing my time improve was a good motivator.

There's been a few people I had no idea were affected by dementia who've said, 'I'm glad you're doing it.'

I finished the challenge and raised £1,125 for Alzheimer's Society, but I'll still be swimming four days a week – it's an addictive thing!

Find out more about Swim for Dementia – please visit [alzheimers.org.uk/swim-dementia](https://alzheimers.org.uk/swim-dementia) or call **0330 333 0804**.

## 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: Swadesh Bala Jaitly

Swadesh Bala Jaitly in Surrey, aged 85 with Alzheimer's.



## What's changed most since your diagnosis?

When I was first diagnosed, I didn't believe it. I thought I was just grieving for my late husband. I started to realise I was forgetting things and could no longer live alone in my house.

I had to move in with my daughter and her family, which was very hard for me as in my culture you shouldn't move in with your daughter after she is married. I was worried about being a burden.

Now, I feel like I am living again, I go out with my family, enjoy playing games with my grandchildren and am much more active.

## What would you take to your desert island?

I love to watch Indian films, prayers and songs on my TV, so I would feel lost without it. I would also take a little shrine with me so I could pray and feel safe.

## How has Alzheimer's Society helped you?

My family ordered booklets from Alzheimer's Society to help me understand what was happening to me and to give me advice on things to help. The information also helped my family to care for me.

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

The Gayathri Mantra, which is a Hindu prayer song. I have always been very religious and when I am anxious or worried this helps me feel at peace and calms me down. This has always helped me during the difficult times in my life. I wake up and listen to it straight away and fall asleep listening to it. I sing along.

## What single thing would improve your quality of life?

I found the pandemic hard, as I had to keep safe and not see too many people. I miss seeing people and would like everything to go back to normal.

I would also like to visit my brother and sister in India, as I worry I may not see them in real life again. I talk to them on the phone and can see them as I talk, but it is not the same.

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

I would go back to when I was a research scientist, as I loved doing experiments in the lab. It was my ambition and dream to do research. I did my PhD at university in Calcutta (now Kolkata), India, and I was the only girl there. This was my happiest time and I was very proud of my work.

## What is your most treasured possession?

A cushion with my husband's face on it. This helps me sleep. When I look at it I feel he is still with me, and when I see him smiling at me it comforts me. I love to cuddle it.



# 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**

**[www.alzheimers.org.uk/get-support](http://www.alzheimers.org.uk/get-support)**

Registered charity No. 296645

21065SD

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

Person living with dementia



# Access for all

Kim Lees, Senior Editor for accessible resources, invites you to help make our information more accessible by joining our Reader panel.

**A**t Alzheimer's Society, we want to make sure everyone can access and understand information about dementia.

This goes beyond making sure people can get information for themselves and the people around them. It's about promoting independence and inclusion too.

Ultimately, access to reliable information can lead people to an earlier dementia diagnosis and to get the kind of support that's right for them.

All too often, people with a disability or sensory impairment aren't able to access important health information, and the same is true for people who don't speak English. This problem isn't theirs to solve, it's ours.

## Your information, your way

As well as our usual print publications and online articles, a lot of our information is available in other formats:

- Translations into different languages.
- Easy Read, for people with learning disabilities.
- British Sign Language (BSL) videos on our website and on DVD.
- Audio versions available online and on CD.
- Large print.

You can access these online or we can post them to you – please visit [alzheimers.org.uk/accessible-resources](http://alzheimers.org.uk/accessible-resources) or call **0300 303 5933**.

We plan to add new translations, audio and video so that more people can access more information.



## Individual needs

The people who need these other formats are a diverse group. For example, a Deaf person who uses BSL as their first language has different experiences to someone who manages their hearing loss using a hearing aid.

That's why we tailor our information and not just the format it's delivered in. To do this effectively, we need to create content with people and not just for them – 'Nothing about us without us,' as the disability rights slogan says.

Learning from people's lived experiences ensures our information is both relevant and culturally appropriate. It can also help us to tackle the myths and misinformation that make it much harder for some people to get a helpful diagnosis.

Whether it's through focus groups, surveys or individual feedback, we create as many ways as we can for people to feel confident about sharing their honest opinions.

## Join our panel

Everyone's experience of dementia is unique. It's important for our information to reflect this by including people with different backgrounds, needs and communication requirements.

You can help us do this by joining our Reader panel. As part of this panel, you would give us feedback about our information and help us make it better. You can feedback in the way that suits you best, whether that's online, over the phone or on printed copies.

Anyone affected by dementia is welcome to join the panel, including people living with dementia and their relatives, friends and carers. We know everyone has different availabilities, so you can take part as much or as little as you are able to.

If you're interested in taking part in our Reader panel, please email [publications@alzheimers.org.uk](mailto:publications@alzheimers.org.uk) for more information.

# In your area



## Dementia Hwb

A pop-up dementia information centre in Swansea has proved such a success that it's been kept open for at least another month.

The Dementia Hwb was set up by Dementia Friendly Swansea in partnership with Alzheimer's Society Cymru, Age Cymru West Glamorgan and other local organisations..

It opened, initially for five weeks, in the Quadrant shopping centre at the end of January.

However, with over 220 visitors getting information and help from volunteers and others staffing the centre in its first month, the pop-up was extended to the end of March.

Hannah Davies, former carer and Dementia Friendly Swansea founder, said, 'Having a loved one diagnosed with a type of dementia is world-rocking, but having the right support at the right time can make it all so much better.

'Looking after Mum, it felt like we lurched from one crisis to another for 10 years, but seeing all this information and all the support that is available to help everyone involved means life with dementia doesn't need to be a constant struggle.'

People have got information at the Dementia Hwb on a range of subjects including diagnosis, replacement (respite) care, finances and power of attorney, as well as emotional support.



## Let's roll!

A supporter in Leeds has raised over £2,500 for Alzheimer's Society in a challenge to roller skate every day for a year.

Laura Taylor began skating daily as part of her efforts to stay well during lockdown.

'It gives me a bit of a safe haven so that I can relax at the end of the day or the beginning of the day, just so that I don't have to think about the rest of the world for a minute,' she told local news.

Laura was on the verge of giving up skating every day when a family member was diagnosed with mild cognitive impairment after having worrying symptoms. This motivated Laura to carry on with her daily challenge while raising funds for us.

Sharing clips on social media, Laura skated in her kitchen when the weather was too bad to go out. She completed her challenge in style, posting a clip of herself playing ABBA's Waterloo on the saxophone while skating.

Ju Lee, Community Fundraiser at the Society, said, 'We were so thrilled to learn that Laura had chosen us to support throughout 2021. Roller skating daily whatever the weather for a full year is a challenge, but Laura smashed it!'



## Excellent Choice

Choice Housing, one of the largest independent housing associations in Northern Ireland, raised over £10,000 for Alzheimer's Society over the last two years despite COVID restrictions, thanks to the creativity and commitment of its employees and tenants.

Staff at Choice Housing chose us as their charity partner in 2020. Although the pandemic hit before fundraising plans could be put in place, they donated £3,000 that year and raised a further £7,355 last year. This was through events such as the 100 Mile Challenge and Belfast City Marathon, as well as an Easter Hamper raffle, Dress Down Friday and Christmas Jumper Day.

Ashleigh Lloyd, on Choice's fundraising committee, said, 'The amazing support from colleagues and tenants has resulted in one of the biggest fundraising totals to date. We are extremely proud of everyone who participated in events, raised awareness and donated.'

Jenay McCartan, Community Fundraiser at the Society, added, 'We're so grateful for all the support we've received from Choice Housing over the past two years. We've been blown away by all their hard work and their determination to make a difference for people living with dementia.'

## Chris Gottlieb, Director of Marketing and Communications



### Why dementia, why the Society?

Like lots of other people, I have deep family connections with the cause. Both dementia and Alzheimer's Society do not have the recognition or prominence they deserve in society. We have a unique opportunity to change this and make positive change for the lives of people affected by dementia. It is a privilege to be doing this role.

### How to fill an unexpected day off?

It would involve some sort of sport and trying to pretend that I am younger than 52! There would be a nice lunch or dinner with the family. A trip to the cinema or theatre would top off a great day.

### Proudest achievement?

Lots of personal moments, including getting married and the birth of my two children. Also my youngest child starring in the West

End and on the BBC in David Walliams's *The Midnight Gang* on Boxing Day, and my oldest being accepted into Cambridge University.

Career wise, leading the redesign of BBC News and winning an award for the best content marketing and communications campaign in the world whilst promoting London tourism.

At Alzheimer's Society, winning PR Week's best external relations campaign for our COVID response work as well as a gold at the Shark international advertising awards for our *Cure the Care System* campaign. The thing I'm proudest of is that these campaigns were ultimately about helping people affected by dementia.

### Worst advice you've been given?

Being told you are not good enough or that you can't do something. It's a red rag to a bull for me!

### Biggest priority for coming months?

To raise awareness of Alzheimer's Society so that we can support more people affected by dementia and attract more supporters. Of course, a big part of this will be through Dementia Action Week from 16–22 May, but it's a focus for me and my team all year round.

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

That they should be valued like any other human being, and that they play an important role in society.

### Most looking forward to?

Raising awareness of Alzheimer's Society for the benefit of people affected by dementia, so more people know how to get support and more people can support us.



## Quick read

After a challenging time supporting their mum in her own home, Nova and her siblings are looking for more outside help.

Doris was diagnosed with Alzheimer's in late 2019, after her children noticed changes in her behaviour and communication.

The family are facing difficult decisions about how Doris can get the long-term care she needs.

Nova, who lives in Wolverhampton, wants better support for families, as well as increased investment in dementia research.

# Tough decisions

Nova is under great strain as her family strives to support her mum. **Gareth Bracken** meets a daughter preparing for the next stage of her mother's care.

**I**t's challenging, deciding what to do when your parents develop a long-term illness and balancing this with work and your own personal wellbeing,' says Nova, whose 84-year old mum Doris was diagnosed with Alzheimer's in late 2019.

With their mum's care needs increasing, Nova and her siblings are turning to more outside help as they strive to decide what is best for Doris.

'It's been a very difficult time, a strain for us all, and her situation is getting worse,' says Nova who, like the others, has been juggling her mum's care with her own work commitments.

'When our dad had dementia, Mum had to give up many of her voluntary community commitments. Mum's wellbeing is the main priority but we're trying to live our lives as well, because we know it's what she would have wanted.'

Nova is calling for better support for people who are caring for someone with dementia.

'More needs to be done in terms of fairer financial support, so that family carers are able to have a better quality of life.'

## Strong-minded

Doris, a great-grandmother who turns 85 in May, came to England from Jamaica in 1960, a year after her husband. Nova was still a baby and didn't join her parents in the country until she was seven. Doris worked as an auxiliary nurse, including night shifts at what was then a children's

hospital in Wolverhampton, in the West Midlands.

'My parents were both very hardworking,' says Nova, who lives in Wolverhampton.

'Mum was feisty and very strong-minded – she stood her ground. She was also very family orientated, a typical Jamaican woman.'

Even after her retirement, Doris was very active in the community. She ran an Age Concern club and was a member of local transportation and hospital boards. She was a retired member of Unison, the union, and actively involved with her Methodist church.

“  
**More needs to be done in terms of fairer financial support, so that family carers are able to have a better quality of life.**  
”

## Not safe

Now semi-retired, Nova worked abroad for 20 years, during which time her dad died with dementia. She returned to England in April 2019 and started to see changes in her mum's behaviour.

'I was noticing things she was doing that weren't safe,' says Nova. 'I came back one afternoon and she'd put a ready meal in the oven still in the paper carton.'

'Another time she had been given a portable stove because of work going on at the house, but she was cooking something that would have caught fire.'

Having also become very repetitive with her questions, Doris saw the doctor in October 2019, before taking a test at the memory clinic the following month. This led to a diagnosis of Alzheimer's.

During the first COVID lockdown, Doris's levels of confusion increased.

'Mum became verbally aggressive towards me, which frightened me,' says Nova. 'She was also not recognising some of her siblings.'

On one occasion Nova called an ambulance because she thought her mum was having a stroke, which turned out to be delirium. Doris also lives with chronic back pain and cornea problems.

## Daunting and sad

With day centres closed because of the pandemic, Nova was feeling the pressure of having to be there continuously for her mum. So the family employed a carer to spend time with Doris during the day,

while Nova and her siblings took turns to go in the evening and stay the night with Doris.

‘Mum developed sundowning, saying it’s not her house. She kept wanting to go back to where I used to live, or go and see her mother,’ says Nova, who received support and advice on these challenges from Anuja Jalota, Dementia Support Worker at Alzheimer’s Society.

With the easing of the pandemic restrictions, the family support Doris to attend a day centre, where she enjoys being around other people. However, many challenges remain, and Doris’s level of need is high.

‘She can be in a foul mood and doesn’t want to go to bed some days,’ says Nova. ‘If you speak to her, she’s quite lucid, but she needs 24/7 support, including personal care, as there are many things she cannot do herself.’

‘Caring for Mum is daunting and sad, and we all have to work as well.’

### Too much

Additional support from a visiting relative allowed Nova to have a few weeks’ holiday. Since her return, the family is trying to decide on the best longer-term support for Doris.

Doris is on a six-month waiting list to have her home assessed for potential adaptations, while another concern is the high cost of homecare.

‘It’s at least £1,000 a week,’ says Nova, who is also critical of how little care workers are paid.

‘What the staff get paid, compared to what we’d have to pay the company, isn’t fair,’ she says. ‘To get good care workers into the profession, they should be valued more.’

### To the fore

Nova believes there are lots of other families in a similar situation and she wants the government to improve the social care system.

‘People will be torn, having to weigh up the care of a person with dementia with the cost of a care home. People are living longer and something needs to be done,’ she says.

‘They need to come up with a strategy, like a scheme which people pay into to cover their costs when they get older.’

And as she prepares for this new stage in her mum’s care, Nova would also like to see better support for families, greater investment in dementia research and more information about dementia prevention.

‘It seems like every other person we hear of has dementia – it’s worrying,’ she says.

‘Dementia needs to be brought to the fore, even more.’



For Caring for a person with dementia: A practical guide (600), visit [alzheimers.org.uk/carersguide](https://www.alzheimers.org.uk/carersguide) or call 0300 303 5933.



Campaign with us for a fairer social care system – see [alzheimers.org.uk/campaign](https://www.alzheimers.org.uk/campaign)

## Donate

£9.90 could provide someone's first conversation with one of our telephone advisors. Please, if you can, donate [online today](#).

# How can you take part?

Research into dementia offers hope. **Gareth Bracken** reports on a specialist service that matches volunteers to vital dementia research studies.



## Quick read

Join Dementia Research is a specialist service that matches volunteers with suitable studies.

As well as covering treatment, diagnosis and risk, many studies look at improving care and quality of life.

Stan, who lives with Alzheimer's and has taken part in studies through Join Dementia Research, encourages others to get involved.

Del and his wife Maureen, who has Alzheimer's, benefited from participating in unexpected ways.

**I**t's only through research that we can understand what causes dementia, develop effective treatments, improve care and hopefully one day find a cure. To achieve this, researchers need volunteers.

Finding volunteers can be a challenge, but Join Dementia Research is a specialist service that's helping to match people with the right studies. Anyone aged 18 and over in the UK – whether they have dementia or not – can register to hear more about opportunities that could suit them.

The studies on offer cover treatments for dementia, reducing the risk of developing dementia, diagnosis techniques and improving quality of life after a diagnosis.

### Force for change

Join Dementia Research was developed by the National Institute for Health Research in partnership with Alzheimer's Society, Alzheimer's Research UK and Alzheimer Scotland.

A special Society helpdesk provides information about how the service works and the sort of studies on offer, and allows people to register over the phone.

Sharon Boulter, Join Dementia Research Telephone Adviser, says people are often surprised that there is a lot more research than just medical trials.

'Researchers are really keen to hear the thoughts and experiences of those whose lives are affected by dementia,' she says.

'Somebody I recently registered over the phone was delighted to be told she had already matched to four studies at the end of the registration!'

Registering with Join Dementia Research doesn't commit you to taking part in a study, it simply means you'll hear about opportunities that could suit you. After registering, you can also access ongoing support.

'We continue as a point of contact,' says Mary Keddy, Dementia Adviser Supervisor for Join Dementia Research. 'We want people to enjoy taking part and to get the most out of the service.'

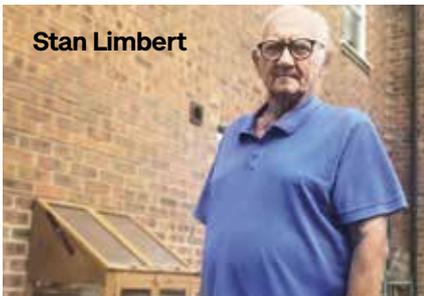
'People feel really proud to take part in research. For research to progress we need more people involved in more studies, so it's about empowering them to be a force for change.'

### Life after diagnosis

Stan Limbert in Merseyside, aged 78 with Alzheimer's, feels a strong sense of purpose from being part of Join Dementia Research.

'I'm getting involved rather than sitting at home, twiddling my thumbs, moaning that things aren't being done,' he says. 'There's life after diagnosis – a lot of us aren't

Find out more about how to get involved in dementia research – call **0333 150 3456** and ask for the Join Dementia Research helpdesk, or email [joindementiaresearch@alzheimers.org.uk](mailto:joindementiaresearch@alzheimers.org.uk)



**Stan Limbert**

fragile little eggs that can break.'

Particularly worthwhile for Stan was an online cognitive stimulation study, which included a variety of activities to stimulate the mind.

'It opened my eyes up about my short-term memory and I learned a fair bit more about myself,' he says.

Stan strongly encourages other people with dementia to register with Join Dementia Research.

'No two of us are alike, so the more people they can get – Lewy body dementia, frontotemporal dementia, young-onset dementia – the better it will be for others in the long run,' he says.

'If you have the opportunity, join it!'

### Something worthwhile

Del Garland and his wife Maureen, who was diagnosed with Alzheimer's in 2018, are both registered with Join Dementia Research.

'Maureen was of the opinion that she'd like to help others – she's been the driver for this,' says Del. 'We're doing something worthwhile.'

The couple have taken part in several studies from home during the pandemic, including Pathfinder, where they gave feedback about some talking therapy sessions they had received.

'It was good for us,' says Del. 'Just talking was useful, and we



**Del Garland and his wife Maureen**

got ideas for how to do things differently, and better, like using Alexa.

'We'd be lost without some of these projects. They help us and give us some answers.'

It was also suggested that Maureen might read more, something she has found very beneficial.

'I needed to keep my mind going, so I started picking up books,' she says. 'It really does help me a lot, to get engrossed in a story.'

Maureen also values the connections she has made with others affected by dementia and the researchers running the studies.

'It's feeling like you're in a team,' she says.

### Feeling empowered

Penny Foulds is Neuroscience Team Leader at MAC Clinical Research, where she oversees recruitment of volunteers for dementia research.

'Some studies can be difficult to recruit for, because many people aren't eligible. Sometimes, clinical trials fail because they can't get enough people,' she says.

'There can be a lot of criteria that people have to meet, and Join Dementia Research allows that initial selection to be done.'

For its most recent Alzheimer's study, MAC recruited nearly half



**Penny Foulds**

of its participants through Join Dementia Research. Penny is currently using the service to recruit people with Parkinson's disease dementia, dementia with Lewy bodies and mild cognitive impairment.

Penny has many personal, professional and voluntary connections to dementia, and is passionate about promoting Join Dementia Research whenever and wherever she can.

'There are so many benefits to taking part in clinical studies,' she says. 'People feel empowered because they are contributing to the progression of drugs for this devastating condition.'

**Donate**

Your donation brings us closer to better diagnosis and treatment for people living with dementia. If you can, please [donate online today](#).

To learn about our research, visit [alzheimers.org.uk/research](https://alzheimers.org.uk/research)

# Golden Memories

Watford Football Club's reminiscence programme takes people with dementia on a journey through the decades. **Gareth Bracken** reports on a group that's become a lifeline for those involved.



## Quick read

Watford Football Club's reminiscence programme uses football, social history and music to evoke personal memories for people affected by dementia.

Golden Memories sessions include exercise, memorabilia and guest appearances from former players. They aim to improve people's social, emotional and physical wellbeing.

June Casey, whose partner Walter used to play for Watford, says the sessions are a lifeline for people affected by dementia.

Golden Memories is part of Dementia Friendly Watford, an initiative from Watford Borough Council.

**W**atford Football Club's Golden Memories reminiscence programme uses football, social history and music to evoke personal memories for people affected by dementia. Based in the Sensory Room at the club's Vicarage Road stadium, the sessions take people with dementia – known as 'guests' – and their carers on a stimulating, entertaining and engaging journey through the decades.

The twice-weekly programme is run by the club's Community Sports and Education Trust, with support from Watford Museum, and funded by the Premier League and Professional Footballers' Association. The popular sessions have featured Watford FC memorabilia and guest speakers, including former players such as club legend Luther Blissett.

'Often people with dementia feel very vulnerable, they feel forgotten, they feel lost. Whereas coming here, they can feel part of

something special,' says Hannah Foster, who set up and ran the group for two-and-a-half years as the trust's Project Officer for Older Adults.

The sessions offer exercise and recreate the excitement of attending a live match, while improving guests' social, emotional and physical wellbeing. The programme is supported by volunteers – who are all Dementia Friends – including Rita Taylor, wife of the late Graham Taylor, Watford's most successful manager.

'It's one big family event, in terms of our volunteers, our staff, the carers, the guests. We all work together to create a family and support network,' says Hannah.

### Lifeline

Among the group's guests are Walter Lees, who has dementia, and his partner June Casey. Walter played over 200 games for Watford in the 1960s and 70s, helping the club win the Third Division in 1969.



Photographs: Premier League

For Golden Memories, see [www.watfordfcsetrust.com/golden-memories](http://www.watfordfcsetrust.com/golden-memories)



‘Golden Memories is a lifeline to people with dementia and their carers,’ June told the Premier League. ‘It’s somewhere to go and socialise. Walter has got to know people and he’s just brighter.’

‘We end up dancing and singing, and you go home feeling, “Well that was good! I’ve got another one to look forward to next week.” For Walter, it’s the centre of his life.’

Walter is full of praise for Golden Memories and those who run the group.

‘If it wasn’t for Hannah and the team, I would be stuck in the house. I don’t know if they realise the goodness they’re doing for people in our situation,’ he says.

### **Ideal place**

Another guest, Bryan Hedley, is a long-time Watford fan who is now living with dementia.

‘My first game my uncle brought me to was in 1939, and war broke out the next day, so football was cancelled from then on,’ he recalls.

Having initially been unsure what to expect, Bryan has really enjoyed the sessions.

‘I must admit, I didn’t know what it was going to be like, and I’ve come and it’s great,’ he says.

‘It’s great to be able to talk to people and see people regularly. And we’ve got such a nice group

here, that it’s so friendly. I look forward to Tuesdays – I had to get up quite early this morning to get organised!’

‘It’s just the ideal place to come and meet people you want to see.’

### **Live shows**

The group had to stop meeting face-to-face during the pandemic, but staff and volunteers stayed in touch with guests via regular phone calls and garden visits, when permitted.

‘They were ringing up regularly, different people, to ask how you are. They stayed on a long while,’ says Bryan.

The team also sent Golden Memory Boxes containing photos and memorabilia, and shared newly-created reminiscence resources. These included a booklet called Journey through the decades, 3,000 copies of which went to Golden Memories guests, older Watford fans and local care homes.

Care home residents were also invited to live entertainment shows over Zoom, which expanded to 45 homes as far as Belfast and Edinburgh, through the involvement of the Salvation Army.

### **Reaching out**

Hannah and her team have worked

closely with Alzheimer’s Society, which led to Society Ambassador Sir Geoff Hurst recording a Christmas message for one of the Zoom shows. Hannah and Luther Blissett also supported Watford Memory Walk last year.

The trust and the Society are both partners of Dementia Friendly Watford. This is an initiative from Watford Borough Council to make life easier for local people affected by dementia.

‘It’s just so important that we reach out within our towns, within our cities, to people living with dementia,’ says Hannah, who is now Dementia Project Manager at the council.

She is also supportive of the Society’s Sport United Against Dementia campaign, which is raising funds and awareness to improve the lives of current and former sportspeople, staff and fans who are affected by dementia.

‘Alzheimer’s Society is a wonderful charity and I think it’s incredible that the Premier League has decided to work with them on the campaign,’ says Hannah. ‘It’s just a wonderful, wonderful partnership.’

Use the directory at [alzheimers.org.uk/dementiadirectory](https://www.alzheimers.org.uk/dementiadirectory) to find support near you.

Visit [alzheimers.org.uk/SUAD](https://www.alzheimers.org.uk/SUAD) to find out more about Sport United Against Dementia.

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

Letter of the month

## Winning memories

Thank you so much for the lovely prize of the Golden Days Memory Calendar. I have attached a picture of what I have done with all the lovely nostalgic pictures.

I have laminated each month's picture and am going to use them at my Sunflower Memory Café to stimulate discussion of memories. They can pass them round and look at lots of different pictures.

I am very happy with this prize and how I can use it to help lots of people living with dementia in my community.

**Sian Thomas, Essex**

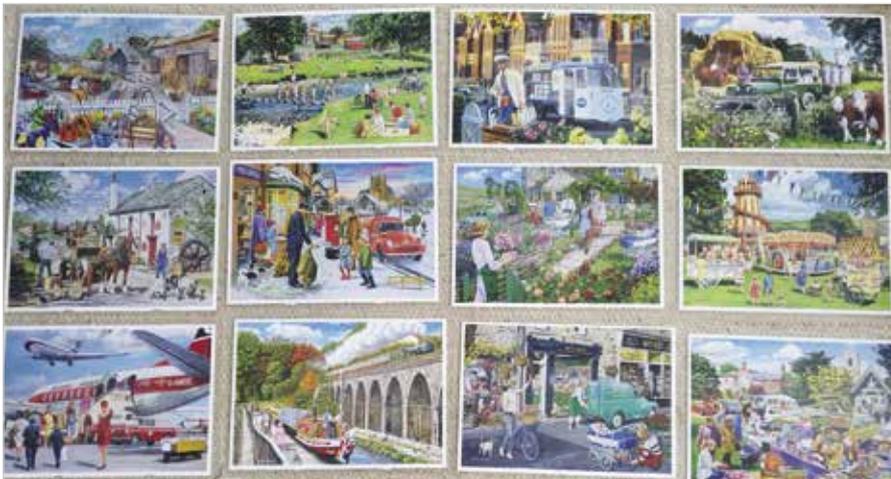
### Response

It's great to see a competition prize being put to such good use – thank you for sharing!

There are a wide range of activity ideas and helpful products in our online shop, see [shop.alzheimers.org.uk](http://shop.alzheimers.org.uk) or call **0300 124 0900**.

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

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



## 3NDWG webinars

The 3 Nations Dementia Working Group (3NDWG) runs regular webinars on a range of subjects relevant to people affected by the condition. You can take part in live sessions or watch recordings of previous webinars.

3NDWG is a network of people living with dementia across Wales, England and Northern Ireland, and recent webinars have discussed having other health conditions as well as dementia, pressures on carers and having a learning disability and dementia.

3NDWG has run 43 webinars, led by panels involving 36 different people with dementia, and there have been over 70,000 views of the online recordings.

Visit [www.3ndementiawg.org](http://www.3ndementiawg.org) and click 'Events'.

### Your turn

Tell us what you think – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk)  
Letters for the June/July issue to arrive by end of 3 May. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

## Seen elsewhere...



When we shared our petition on Facebook to keep free lateral flow tests for people visiting relatives and friends in care homes, Dawn Wakeford commented:

🗨️ Signed and shared. Disgraceful that we are having to pay for an LFT to visit our loved ones. For some relatives it may mean that they will have to reduce the visits, very unfair on the very elderly who yet again are hit by this government's insensitive greed. 🗨️



On Twitter, Alzheimer's Support in Wiltshire posted pictures to celebrate information sessions organised by them and Dementia Friends Champion Terry Ruddock at a local school:

🗨️ Important conversations about #dementia – and new #DementiaFriends – at Warminster School yesterday. Thanks to champion Terry and all at the school @Warminster1707 @WarminsterP\_Dev @DementiaFriends @GMorrisonCEM #Warminster 🗨️



Warminster School upper sixth pupils Lily and Freya.



On Talking Point, our online community, englishalien thanked the many members who answered their question about deputyship for a recently diagnosed aunt:

🗨️ This forum is so helpful. It feels like you're all helping me finely balance the scales with your answers and advice. I appreciate this. 🗨️

## Let's Reimagine

An international group of people affected by dementia has released an inspiring song and video in a campaign to transform the culture of dementia.

Reimagining Dementia, which describes itself as a creative coalition for justice, teamed up with musician Simon Law to create an original song called Let's Reimagine. It features people living with dementia as soloists, chorus members and through spoken word.

Watch the video and find out more at [www.reimaginingdementia.com](http://www.reimaginingdementia.com)

## Alexa app pilot

A technology firm is looking for people to try out a new voice app for Amazon Alexa that aims to support people with dementia to live well at home.

GG Care has developed an app for use with Amazon's virtual assistant to help the person maintain their independence with everyday tasks. It provides stimulation, makes it easier to stay connected and can provide a carer with helpful information. Designed to work with an Amazon Echo device, the app is free to use though has some paid-for features.

People accepted onto the pilot get free access to paid-for features, and those joining before 1 May will also be provided with an Echo device.

To find out more, email [contact@gg.care](mailto:contact@gg.care) with the subject 'Pilot'.

## Vegetarian pledge

Vegetarian for Life is encouraging care providers to commit to respecting the values of the people using their services.

National Vegetarian Week coincides with Dementia Action Week this year, 16–22 May, and the charity wants providers to sign its Memory Care Pledge. This has five action points to ensure vegetarians and vegans with capacity or cognition issues are offered meals, drinks and snacks that uphold their ethical beliefs.

For more about the Memory Care Pledge, see [www.vegetarianforlife.org.uk/pages/pledge](http://www.vegetarianforlife.org.uk/pages/pledge) or call 0161 2570887.



Our panel looks at a range of clothing and footwear designed to help dressing, without compromising on attractiveness and comfort.

## Clothes and shoes

**W**e took specially designed clothes and shoes to Worthing's Dementia Voice local group for them to try out and review. This longstanding West Sussex group of people living with dementia meets regularly to discuss local and national topics, and to influence our and others' work.

The clothing and footwear have been produced to be easier for people to put on and take off, including people who have problems with cognition, co-ordination or movement.

### Womenswear

The Able Label uses velcro fasteners, often behind decorative buttons, and design clothes to reduce the need to pull them over your head. If you fasten the velcro while clothes are being washed, it should last as long as the clothes do.

We gave clothes to two women from the group in advance of the panel.

Pauline, who tried a 'Tabatha' T-shirt in cobalt blue, said, 'I really like the material, as it feels soft and comfortable.'

She suggested that more closely arranged velcro pads could give a more precise fit, but said, 'The fit is good and has room for movement.'

Chris, a dressmaker, also liked the 'Maisy' lightweight mac she'd tried beforehand.

'It's beautifully made,' she said, and she liked its soft finish. 'That's very wearable.'



Chris in a 'Maisy' mac.



Pauline in a 'Tabatha' T-shirt.

'I don't think it's expensive for what it is,' she added, 'and it would last long.'

Looking at the 'Janet' nightdress, made from jersey cotton and opening at the front, Chris said, 'It's nice and warm. Absolutely perfect for the winter, lovely material.'

'And it's my favourite blue – I love it!'



### Menswear

The group looked at three shirts – a brushed cotton 'James', a smarter 'Martin' and short-sleeve 'Hugh' – plus two trousers and a cardigan.

Steve loved the shirts. 'I like that it looks like you've got buttons, brilliant idea,' he said. 'It would help a lot of people, and they look good as well, don't they?'

Emery added, 'I like the check – it makes me feel like I'm on safari!'

John particularly liked how comfortable and warm the 'James' felt, though he could feel the top velcro fastener against his chin when he put his head down.

Dave tried on the men's cardigan, saying, 'It feels nice, lovely and light as well,' and David, sitting next to him, approved too.

Stan appreciated the expandable waist on the 'Blake' grey trousers, adding, 'My waist tends to expand!'

While 'Blake' has only velcro at the fly, the sand-coloured 'Aubrey' trousers that John

(Left to right) Force, Voyage and Excursion shoes.



'James' shirt.

tried has a zip with one velcro pad at the top.

He said he liked these 'chino type trousers,' but would prefer a larger toggle on the zip, since this one was a bit too small to get hold of easily.

The group agreed that the clothes were good value for money, given the difference the fastenings would make.

'Even if you go into Marks, if you get a single shirt, you might end up paying 30 or 40 quid for it,' said Stan.

### Footwear

Friendly Shoes are designed by an occupational therapist to be easy to get on and off as well as comfortable and safe, with removable memory foam insoles and secure grips.

There are three models in a range of colours – Voyage and the lighter weight Force open using zips along the side, while the zip on the Excursion runs around the heel.

Trying the Voyage, Stan said, 'I've never gone in for a trainer style, but I like the side zip, that is a great idea. The quality is very good.'

John also thought they were priced reasonably.

'The shoes I have on now are expensive,' he said, 'but I have to use a long shoehorn to put them on. But with these I can just put them on, it's easy.'

Chris agreed, 'They're good value for money.'

Visit [shop.alzheimers.org.uk](http://shop.alzheimers.org.uk) or call **0300 124 0900** for these and other products that help people affected by dementia to live well at home. As with some other specially designed products, you don't have to pay VAT if they're for a person with dementia – tick the box stating you're eligible for VAT relief at checkout.

Prices at 1 April (all excluding VAT): 'Maisy' mac £49.17, 'Tabatha' T-shirt £30, 'Janet' nightdress £37.50, 'James' shirt £43.33, 'Martin' shirt £40.83, 'Hugh' short sleeve shirt £37.50, men's cardi £45.83, 'Aubrey' trousers £39.17, 'Blake' smart trousers £45.83, Force shoes £59.99, Voyage shoes £69.99 and Excursion shoes from £74.99.



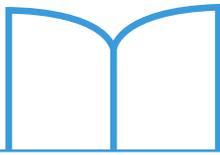
'Blake' trousers.



'Aubrey' trousers.

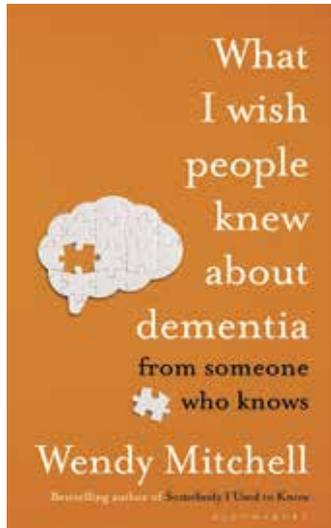
## Win a top or shoes

See p39 for chances to win a shirt or T-shirt from the Able Label and footwear from Friendly Shoes.



We read this second book from Wendy Mitchell, who was diagnosed with young-onset dementia aged 58.

## What I Wish People Knew About Dementia



**M**any readers will recognise our Society Ambassador Wendy Mitchell, a blogger and activist whose first book – *Somebody I Used to Know* – is a Sunday Times bestseller.

*What I Wish People Knew About Dementia*, which Wendy also wrote in collaboration with Anna Wharton, has made a similar splash.

Caroline Branney, who manages our Dementia Knowledge Centre, says, 'Her second book is also worth reading if you have any interest at all in dementia.'

'Written in a chatty, readable style and filled with many anecdotes and stories, the book is packed with really insightful observations.'

Peter Turner, a reader in West Yorkshire, who says he 'avidly devoured' it, adds, 'I found it to be a very informative yet easily read book.'

Janet Dandy in Lancashire, whose mother-in-law was diagnosed with dementia, says, 'I was inspired and greatly admiring to learn that the author is able to

live alone, through the help of her family, friends and neighbours.

'And though she is honest about her struggles and frustrations, it was wonderful to read how she has found ways to still live an active and interesting life, plus contribute so much to research and more understanding of dementia.'

### Mines of information

'Wendy emphasises that everyone is different,' says Caroline, 'just as they all were before dementia. In this book, she includes other people's experiences as well as her own.'

Peter says, 'The individual sections are mines of useful information, drawn up in a storytelling way with humorous anecdotes helping to illustrate the points. I particularly liked the "senses" chapter and how it covered areas I would never have considered.'

Janet agrees, 'The book covers problems regarding food issues, room and building design, relationships, communication, impact on emotional capacity and information about sensory hallucinations, such as odours – the latter of which I had not heard about previously.'

'Wendy also brings a positive viewpoint about how modern technology has assisted her, including the use of Twitter, Alexa and phone apps.'

### Crucial attitudes

'The main message I took from the book,' says Janet, 'was that the attitudes, language and

communication from others (especially professionals) can be so crucial, and that so much could still be improved upon.'

Caroline says, 'Wendy has strong opinions on many areas including relationships, social isolation, environment and living alone with dementia.'

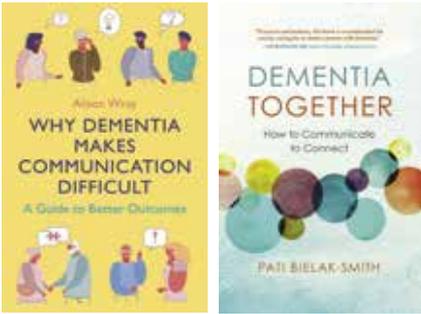
'She criticises the diagnostic process as being "far too clinical" and makes it very clear that there is much room for improvement in professional language used around the condition – for example, terms like "challenging behaviour" – and in attitudes towards people with dementia.'

Peter says, 'I thought I knew quite a lot about dementia having had it thrust into my life in 1990, but I have learned an amazing amount from this book on many simple aspects of a person's daily life with dementia.'

'I only wish it had been available to me all those years ago when dealing with my father's dementia. If it had, I would not have made so many mistakes. I hope others discover it in time to help their present situations.'

**What I Wish People Knew About Dementia, by Wendy Mitchell (Bloomsbury, 2022), 240 pages, £14.99, ISBN 978 1526634481. Also an ebook.**

# Learning disabilities and dementia resources



## Your turn

We invite you to read one or both of these books for next issue:

- **Why Dementia Makes Communication Difficult** by Alison Wray (Jessica Kingsley, 2021), 192 pages, £22.99, ISBN 9781787756069.
- **Dementia Together: How to Communicate to Connect** by Pati Bielak-Smith (Puddledancer, 2020), 224 pages, £16.99, ISBN 9781934336182.

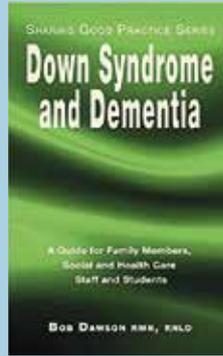
Tell us what you think about either of these books, both of which are also available as ebooks. Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) by the end of 3 May so we can share your comments.

## Book giveaway

We have three copies of each of these books to give away – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) by the end of 13 April quoting ‘Why’ for a chance to win Alison Wray’s book and ‘How’ for Pati Bielak-Smith’s (see p39 for terms and conditions).

### Discount codes

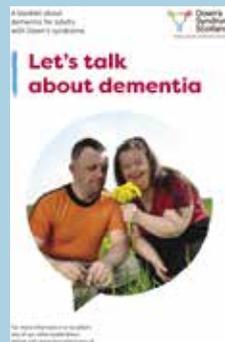
For a 20% discount on Alison Wray’s book from [uk.jkp.com](http://uk.jkp.com), use the code **ALZ20** at checkout. Get 25% off Pati Bielak-Smith’s book before the end of July from [www.gazellebookservices.co.uk](http://www.gazellebookservices.co.uk) using the code **TOGETHER22**.



### Down syndrome guide

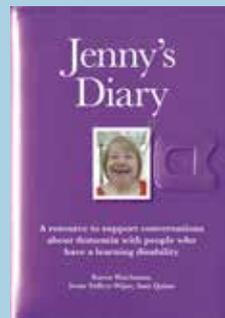
This book uses real questions from the author’s training sessions to identify the main issues affecting people with Down syndrome who develop dementia, and to stimulate discussion and further reading.

**Down Syndrome and Dementia: A Guide for Family Members, Social and Health Care Staff and Students**, by Bob Dawson (The Choir, 2020), 86 pages, £8.99, ISBN 978 178963 1678. Also available as an ebook.



### ‘Let’s talk’ workbook

‘Let’s talk about dementia’ is an Easy Read workbook from Down’s Syndrome Scotland to help a person with a learning disability understand dementia, whether their own or someone else’s. See [www.dsscotland.org.uk](http://www.dsscotland.org.uk) and click ‘Resources’ then ‘Publications’, or call **0300 030 2121**.



### Jenny’s Diary

This booklet and set of postcards, developed through Society-funded research, support conversations about dementia with people who have a learning disability. Versions include one that uses the term ‘intellectual disability’ as well as ebook format and translations.

Visit [www.learningdisabilityanddementia.org](http://www.learningdisabilityanddementia.org) and click ‘Jenny’s Diary’.

### Our factsheets

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

- Learning disabilities and dementia (430) factsheet.
- Two 16-page A4 factsheets with simplified information for people with learning disabilities – Easy Read factsheet: What is dementia? (ER1) and Easy Read factsheet: Helping a person with dementia (ER2).



**‘I’m really struggling financially on my pension, especially with the cost-of-living crisis. What support can I get to help make ends meet?’**

## Pension credit



Photograph: Freemages.com/Sammil\_Babe

If you’re over state pension age and on a low income, you may be eligible for the Guarantee credit element of Pension credit. This gives you extra money to help with living costs, by topping up your weekly income.

It’s estimated that two out of five people entitled to this miss out because they don’t claim it.

### Who can claim?

Whether you’re eligible for Guarantee pension credit depends on your income and how much you’re seen as needing. For example, the amount needed to live on will be set higher if you’re disabled or someone’s carer.

When calculating your income, some benefits such as Attendance allowance and Personal independence payment won’t be included. This means you can keep them in addition to getting Pension credit.

If you live with a partner or spouse, you must both be over state pension age to claim. The income, savings or capital you both have affects how much Pension credit you may get. If you have over £10,000 in capital – not including the home you live in – you can still claim, but you will get less.

### Passport to more

Even if Guarantee pension credit only tops up your income by a small amount, claiming it could allow you to access other types of help. These can all add up to make a big difference, including:

- a free TV licence if you’re over 75
- full Housing benefit and Council tax support
- free dental treatment
- help towards the cost of glasses and hospital travel fares
- help with the cost of heating your home.

You may also qualify for mortgage interest loans and budgeting loans, if you need money for things such as furniture, home maintenance or clothing. Unlike the help listed above, these are loans that must be paid back, so make sure it’s right for you before applying.

### Applying and more help

Visit [www.gov.uk/pension-credit](http://www.gov.uk/pension-credit) for more information about Pension credit and to apply for it. Some organisations, such as those

listed at the end of this article, could give you a free benefits check and help with filling out forms.

If you’re struggling to make ends meet in the meantime, you may be able to get short-term help with food, bills or household items. Contact your local authority to see what’s available in your area. This could be through something called the Discretionary Assistance Fund in Wales, Discretionary support in Northern Ireland, or a welfare assistance scheme or household support fund in England.

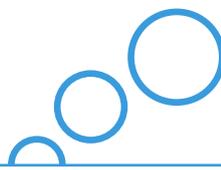
### Benefits checks and advice

Age UK  
[www.ageuk.org.uk](http://www.ageuk.org.uk)  
0800 055 6112

Turn2us  
[www.turn2us.org.uk](http://www.turn2us.org.uk)  
0808 802 2000

Citizens Advice  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)  
0800 144 8848 (England)  
0800 702 2020 (Wales)

Advice NI (Northern Ireland)  
[www.adviceni.net](http://www.adviceni.net)  
0800 915 4604



## Shopping for clothes

Photograph: FreeImages.com/danjaeger



**The idea of shopping for clothes will be a delight for some people with dementia and a chore for others. However, even if it's not someone's favourite activity, it might be possible to turn it into a good day out.**

### Choices

Decide whether making a list beforehand or just browsing would suit the person best. Think about where you could take breaks to relax and recharge.

As well as high street shops and supermarkets, consider vintage and charity shops for variety and interest. A specialist shop may help someone who likes clothing of a particular style or culture, or needs sizes that aren't catered for elsewhere.

Some clothing is designed to make dressing easier while still looking good. For example, the Able Label clothing and Friendly Shoes are available from our online shop – see [shop.alzheimers.org.uk](http://shop.alzheimers.org.uk) or call **0300 124 0900**.

### Access

Some shops are 'dementia friendly', meaning they try to make things easier for customers affected by dementia.

Ask for an accessible changing room, with space for two people, for someone who needs help trying on clothes. If it's easier to try them on at home, buy from retailers who accept returns.

Some local councils offer a community transport service to help visit the shops, and this might even pick you up from home.

ShopMobility provides low-cost (or sometimes free) mobility equipment hire – contact your local ShopMobility UK centre or see [www.shopmobilityuk.org](http://www.shopmobilityuk.org)

Alternatively, you could browse for clothes together at home from catalogues or online.

As a person's dementia progresses, it's important they have the capacity to continue making decisions about spending. They may also need support to stay safe online.

Visit [alzheimers.org.uk/publications](http://alzheimers.org.uk/publications)

or call **0300 303 5933** for our Supporting a person with washing and dressing factsheet (504) and The activities handbook: Supporting someone with dementia to stay active and involved (77AC).

### Over to you

**Do you have any tips about shopping for clothes that we could share next issue? Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) by 4 May.**

## Baking: What you said

**Yankeeabroad**, on Talking Point, says, 'My dad used to be the master baker – cakes, brownies, and cookies from scratch and waffles.

'We've moved to using mixes and prepared frosting (thank you Betty Crocker!) now, as it's much easier for him to manage to mix. And he always does it with me (daughter) or his caregiver. We can just supervise or help a lot if he is having a confused day. We

sometimes make extra waffle batter to leave in the refrigerator so he can have "fresh waffles" on another day.

'Overall, this seems to keep his brain actively engaged and he's more alert.'

**canary** was reminded of a late fellow member, Barry Pankhurst. 'Barry's baking thread', which compiles many tips that he shared

over the years, can still be read on the online community.

Barry also published two books in 2014 – **Master Baker Barry's Bakery Recipes Whilst Living with Alzheimer's** (ISBN 9781495913013) and **Master Baker Barry's Recipes for Success Whilst Living with Alzheimer's** (ISBN 9781497344181).



Talking Point members' and readers' advice for someone whose relative or friend with dementia seems 'like a different person'.

## A 'different person'

'Damage to the brain leaves its mark and, depending where in the brain is affected, causes different patterns of behaviour.

'I've had to change too, adapting to what my husband needs and how to meet those needs. So, we are both different people.'

**jennifer1967**

'The way that I approached my mum with her dementia was like meeting someone different for the first time.

'I find the different stages she is at as a new experience for me to learn something new about my mum and a little bit more about "her world".

'It is tough sometimes, I will not lie. But being in my mum's world sometimes is exciting and teaches me something new.'

**Sarah Williams, East Sussex**

'My husband got angry, shouted and swore at me, something he had never done before, as we had never had a cross word in our 25 years together.

'Talk to someone and start stepping back from it, so it doesn't become personal. There is too little help with behavioural issues, and I spent many a night in tears.'

**Thethirdmrsc**

'When my loving, beautiful mum tells me that I want her dead, I try to think about the damage wrought in her brain by this disease.

'I think about how these unbidden, unwelcome changes inside her brain are changing her... She is frightened.

'I think of this, I keep the science, the understanding, the compassion at the front of my mind and yet still it hurts and hurts and hurts.'

**Wildwoodflower**

'Remember the person before their dementia, because the person before you now will start to exhibit many changes and some will be painful to see. It's not their fault when these changes happen.

'I never once heard my dad swear until he suffered with Alzheimer's and vascular dementia. I witnessed some extreme bursts of anger, rudeness and accusations that I knew were totally untrue, it was not the Dad I knew.'

**Wildflowerlady**

'Accept this is the disease and not your loved one's fault. Accept this is how they are today but that tomorrow may be different. Take a break, let some time pass and sit quietly with them and hopefully you will see that they are still in there.

'My dad would be mortified to know how he speaks to the carers during personal care, but they accept it isn't his fault.'

**PippaS**

'If the changes are just too great and you really can't do it anymore, don't feel guilty because it's not your fault and nothing you can do will change how things are now.'

**Jaded'n'faded**

'The person may in some ways appear "like" a different person, but they are the same person with an invisible injury which has affected how their brain works

'One daughter I met said it helped her to have seen the image of the scan of her mother's brain, so saw for herself how much damage there was.'

**Shedrech**

'Maybe I'm not in that stage yet. My personality has changed. But for the best. I'm nicer, don't complain about anything, I have a mini meltdown occasionally, but Hubs brings it under control.'

**Happy Hampton**

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



## Next issue: False accusations

Do you have any advice to deal with how it feels if you're falsely accused of something by a relative or friend who has dementia? Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk)

## The Able Label

We have a choice of either a Tabatha cobalt blue T-shirt or Harvey coral/blue short-sleeve shirt for two lucky winners drawn from correct entries received by end of 12 May.

**Q: The velcro fastenings on clothes from the Able Label should last as long as the clothes do if you:**

- A. Fasten them when washing the clothes.
- B. Leave them unfastened when washing the clothes.
- C. Speak to them nicely as you fasten or unfasten them.



## Friendly Shoes

We have a pair of Voyage black unisex shoes, in sizes 4–12, for one winner drawn from correct entries received by end of 5 May.

**Q: The memory foam insoles in Voyage shoes are:**

- A. Unforgettable.
- B. Removable.
- C. Incorrigible.

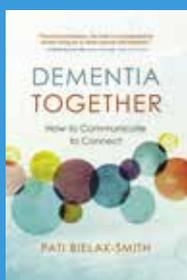
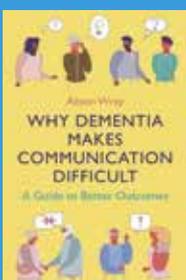


Send us your answers with your name and address – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk)

**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 *Why Dementia Makes Communication Difficult* by Alison Wray or *Dementia Together: How to Communicate to Connect* by Pati Bielak-Smith.



### What I Wish People Knew About Dementia

The five readers who each won a copy of *What I Wish People Knew About Dementia*, by Wendy Mitchell, were L Magem in Norfolk, J Dandy in Lancashire, P Turner in West Yorkshire, J Nunn in Greater London and L Appleby in Tyne and Wear.

### Rosebud competition

J Winsper in West Midlands won a Rosebud Reminder Clock, and O Rowse in Warwickshire won a Talking Time Pal. Answer: The latest Rosebud Reminder Clock has been improved thanks to feedback from people affected by dementia.

### Greeting cards competition

Y Rose in Warwickshire won a selection of 10 Eco Seed greeting cards, and D McKillen in County Antrim won five cards. Answer: If you send someone an Eco Seed greeting card, they can plant the card in soil for wildflowers to grow.



**This year there are Trek26 events taking place in seven breathtaking locations across the UK from the Lake District to South Devon Coast.**

It's not too late to sign up to take on your own 13 or 26 mile Trek26 challenge! You'll join hundreds of others who are also walking to stop dementia in its tracks.

**Use code TOGETHER20 for 20% off your registration fee.**

Sign up by **scanning the QR code**, visit [www.alzheimers.org.uk/trek26](http://www.alzheimers.org.uk/trek26) or call **0300 222 5808** for more information.



**Trek26**