

# Dementia together

April/May 2020  
Alzheimer's Society's magazine

## Inside support

Prison focus

## See the person

'This is me' in hospital

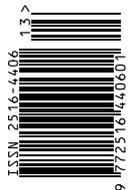


## Respect due

Don't let us down

## Also in this issue

Dementia Connect online  
Enjoying languages  
Popular products



# Change the journey

A different life



# Welcome

**A**s we go to press with this issue of the magazine, there is uncertainty and concern about what the impact of coronavirus will be on the people using our services, our supporters and the wider community.

However it has affected you, we hope that you are staying well. If you need support, visit [alzheimers.org.uk/getsupport](https://alzheimers.org.uk/getsupport) or call **0333 150 3456** to find out how we can help.

With our new Chief Executive Officer, Kate Lee, in place (see p5) and with your continued support, we're in a strong position at Alzheimer's Society to tackle the many challenges facing us all.

There are so many ways for you to unite with us against dementia, and our magazine is here to provide inspiring real-life stories and ideas to help you make a difference. As ever, please make sure that your family, friends and colleagues know how to subscribe (see below).

**Danny Ratnaik**  
Magazine Editor

**Questions about dementia? See p33.**

**Every donation to us helps change the lives of people affected by dementia – see [alzheimers.org.uk/give](https://alzheimers.org.uk/give) or call 0330 333 0804.**

**Dementia together is the magazine for all Alzheimer's Society supporters and people affected by dementia.**

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## Coronavirus (COVID-19)

Alzheimer's Society has called for the government to make sure that people affected by dementia get the support they need as COVID-19, the illness caused by a new strain of the coronavirus, spreads.

For up-to-date information about coronavirus (COVID-19), visit [www.nhs.uk](http://www.nhs.uk)

If you are concerned about symptoms, visit [111.nhs.uk](http://111.nhs.uk) or call 111 for advice.

## Dementia Action Week: Moving to later in year

Coronavirus has meant the postponement of many events, and this includes Dementia Action Week.

To help efforts to slow down and reduce the spread of COVID-19 – the illness caused by this new strain of coronavirus – we're moving this important date in our calendar from May to later in the year.

Visit [alzheimers.org.uk/DAW](http://alzheimers.org.uk/DAW) or call 0330 333 0804 for up-to-date information.



## Dementia Connect online

We've launched new tailored online support for people affected by dementia. Dementia Connect online support is available round the clock through our website. Answer a few simple questions about yourself, or someone you know, to get personalised, relevant information and advice. From guides on dementia to advice on making your home dementia friendly, get the information about the things that matter to you. If you need further support, you can request a call from our dementia advisers, who should be in touch with you within a week. Find our new service at [dementiaconnect.alzheimers.org.uk](http://dementiaconnect.alzheimers.org.uk)

## Social care crisis ignored

Alzheimer's Society says it is 'astonishing and crushing' that social care was ignored in the recent Budget.

Money was provided for the NHS and local authorities to deal with coronavirus, but the Chancellor's announcement contained no additional investment in social care.

'Money to deal with coronavirus is good news – the government needs to say how it's going to be used to protect vulnerable people with dementia,' said Sally Copley, our Director of Policy and Campaigns.

'The fact that the Chancellor appears to have completely ignored social care is astonishing, and crushing for people with dementia.'

We recently launched a new animation to highlight our Fix Dementia Care campaign, which is also being supported by Oscar-winning actor Glenda Jackson.

Watch the animation and support our campaign at [alzheimers.org.uk/fix](http://alzheimers.org.uk/fix)



## 1 Million Minutes Award

Danny Brown, who lives with vascular dementia in Northern Ireland, won the Dame Barbara Windsor Award at Good Morning Britain's 1 Million Minutes Awards. Danny was recognised by the judging panel for his commitment to helping people with dementia combat loneliness.

With the support of Alzheimer's Society, Danny has striven to break down stigma about dementia. He offers personal support to help others in his area come to terms with the condition, and he raises awareness on television and social media.

## Crowning glory

Alzheimer's Society is the new official charity partner of paint manufacturer Crown Paints. We came out on top following a vote among the firm's 1,100 employees to select a cause to support for the next three years. Crown Paints is now planning numerous fundraising events across its offices and facilities.

## What to tackle next?

We want you to tell us which of the challenges of dementia we should be tackling next. By sharing and voting on these on our Innovation Hub website, you'll help us to decide which would make the greatest difference for people affected by dementia. Visit [innovationhub.alzheimers.org.uk](http://innovationhub.alzheimers.org.uk) – we'll be looking for new challenges to tackle for five weeks from mid April.

# Directions

It is certainly a testing time to be joining Alzheimer's Society as the CEO, but I couldn't be more proud to be doing so.

I've seen first-hand the devastation of a dementia diagnosis on individuals and families in normal times, without the social isolation and despair brought by coronavirus. I've also seen the power of the Society's support at this time and it is absolutely inspirational. It's humbling to think I now have an opportunity to shape that work and the future of this incredible organisation.

Recent achievements of the Society, including successfully launching our incredible Dementia Connect online service (see p12), have come just in time to underpin our coronavirus response. Along with our existing ways to provide support (see p33) – and innovations such as 'virtual' Singing for the Brain sessions – we are proud to be reaching hundreds of thousands of people struggling to cope as they remain isolated at home.

I couldn't be prouder of the Alzheimer's Society team. I want everyone that works here and everyone who comes into contact with us to have a great experience, and I know some of the allegations in the media about our culture have made very difficult reading for anyone associated with the Society. You rightly have high expectations and standards, and I intend to prove to you that your trust in us is well deserved.

Finally, I want to say a particularly huge thank you to all our glorious donors and supporters. Like every UK charity, we have had to cancel many events due to coronavirus, which has hit our finances very hard. We have been humbled by the incredible support that we've received – we need you now more than ever. Thank you.

In unity, with you, against dementia,

**Kate Lee**  
Chief Executive Officer



### Tea for everyone?

Media reports about a recent study suggested that drinking tea would reduce your risk of developing Alzheimer's, but this could be misleading.

The US study involved 921 people, aged 81 on average, who did not have Alzheimer's. Over a period of around six years, they regularly answered questions about their lifestyle, including how often they ate certain foods. During this time, 220 of them developed Alzheimer's.

The people whose diet contained more of certain types of flavanols – an antioxidant found in tea as well as nearly all fruit and vegetables – seemed to be less likely to develop Alzheimer's. This was the case even after the results were adjusted to account for other factors such as lifestyle and medical history.

James Pickett, Head of Research at Alzheimer's Society, said, 'Early-stage research in mice does show flavanols might reduce the build-up of toxic proteins in the brain that we know are involved in Alzheimer's. This new study in people isn't definitive about whether flavanols can lower dementia risk, and it definitely doesn't provide enough evidence to say that drinking tea, and eating food rich in flavanols, will ward off dementia. But the results do suggest we should keep investigating the potential of flavanols.'

'Our researchers are currently looking at a specific flavanol called epicatechin to understand exactly which components are responsible for slowing the build-up of toxic proteins.'

**Visit [alzheimers.org.uk/reducemyrisk](http://alzheimers.org.uk/reducemyrisk) to see what people can do to reduce their risk of developing dementia.**

## It's everyone's journey



Alzheimer's Society partnered with the Department for Transport on their campaign to make public transport more inclusive.

'It's everyone's journey' used animations, travel posters and announcements on public transport to highlight how our actions can have a huge impact on journeys of disabled fellow travellers. We worked with the campaign to make sure it represented the experiences of people living with dementia.

In another piece of work, we've also created an information card to help bus companies be more dementia friendly and a 'Top 10 tips' booklet for bus drivers, providing advice on how they can support people living with dementia.

## Jelly Drops launch

A new range of sweets designed to increase a person's water intake is being made available with Alzheimer's Society support.

The sugar-free, vegan Jelly Drops – which contain 95% water – were invented by Lewis Hornby after his grandmother, who has dementia, was hospitalised with dehydration.

Alzheimer's Society supported the development and testing of Jelly Drops through our Accelerator Programme, which invests in innovative ideas to improve people's lives.

**To find out more about Jelly Drops, visit [www.jellydrops.co.uk](http://www.jellydrops.co.uk)**



## Research priorities

We have written to every MP in the UK to highlight the key areas of research that will make the biggest difference for people affected by dementia.

The government's election manifesto pledged to double dementia research spending over the next decade, which should mean an extra £800 million.

We want more research into prevention and technology that will improve dementia care, as well as into treatments and a cure. **Learn more about our research at [alzheimers.org.uk/research](http://alzheimers.org.uk/research)**



## Cupcake Day is coming!

Cupcake Day is back and whether you're a baker, faker or just want to rise against dementia, anyone and everyone can get involved! Join in the fun and host a bake sale with friends, family, colleagues and neighbours on 18 June or any day that works for you. By hosting a Cupcake Day, you'll get to enjoy some scrumptious treats knowing you're helping to change the lives of people affected by dementia.

Sign up now at [alzheimers.org.uk/cupcakeday](http://alzheimers.org.uk/cupcakeday)

## Memory Walk: Who will you walk for?

Registration is open for this year's Memory Walk! The family-friendly sponsored walks are taking place this autumn throughout Northern Ireland, Wales and England, and all ages and abilities are welcome.

Memory Walk is the perfect opportunity to get together with friends and family, enjoy the great outdoors, remember loved ones and create new memories.

Join thousands of others to help fund pioneering research into life-changing dementia prevention, cure and care – you can change the future for people affected by dementia.

Register at [memorywalk.org.uk](http://memorywalk.org.uk) or call 0300 330 5452 (local rate).



## In brief

### Games and activities 10% discount

Looking for activity inspiration? Our online shop has got you covered. Enjoy 10% off a range of games, puzzles and sensory products designed for people with dementia. Use the code DAW10 at checkout to get your discount.

See [alzheimers.org.uk/shopforactivities](http://alzheimers.org.uk/shopforactivities)

## Upholding rights

New guidance from the National Dementia Action Alliance aims to help care providers to protect the rights of people affected by dementia. The guidance – Dementia Statements: Through a legal lens – includes practical examples.

For more about the National Dementia Action Alliance, see [www.nationaldementiaaction.org.uk](http://www.nationaldementiaaction.org.uk)

## Don't miss...

We've designed our new Dementia Connect online service with your help. See p12.

Enjoying learning a language could help you to stay well. See p13.

We're telling the government how new research funds should be spent. See p17.

'This is me' improves dementia care by sharing key information. See p22.

Side by Side supports people with dementia to carry on doing the things they love. See p32.



# Change the journey

Having feared the worst after his dementia diagnosis, Masood Qureshi is now focused on changing people's perceptions. **Gareth Bracken** meets a man who wants others to benefit from his experiences.

**‘For the first couple of years I was scared, frightened, but now I’m more concerned about changing other people’s perceptions,’ says Masood Qureshi.**

Masood was diagnosed with Alzheimer’s and frontotemporal dementia (FTD) in 2011, aged 54. After finally accepting his dementia, Masood wants to raise awareness of the condition and to fight stigma about it. He wants his experiences to benefit other people in a similar position.

‘While no one can change the outcome of dementia, with the right support I think you can change the journey,’ he says.

## Common ground

Masood, now 63, grew up in Pakistan, raised mostly by his mother, with aunties and uncles also around. His father worked in England where Masood, then in his mid-teens, and his mother joined him in 1971.

‘The host community accepted and welcomed us,’ says Masood, who attended a Catholic school in Stoke-on-Trent, the Staffordshire city in which he still lives.

‘I belonged to a religious Muslim family, but the school was keen to listen to me. We actually had quite a lot in common faith-wise – we explored it.’

Other aspects of English life took a bit more adjusting to.

‘We’d never experienced so much cold,’ says Masood, who is widely known as Maq.

‘It was an experience seeing snow for the first time. On TV it looked so nice to watch, so I couldn’t understand how something so harmless could cause accidents!’

## Business venture

In the mid-70s, with his father taken ill and the family in need of income, Masood looked for work. He started as an apprentice at tyre manufacturer Michelin, working his way through the ranks until he left the company when it moved back to France.

He returned to college to learn bookkeeping and accountancy, and then started his own business, which he ran for around six years. He also supported local people and organisations as a translator, interpreter and immigration adviser, and held senior positions with religious organisations.

Masood’s wife died in 1998, two years after a breast cancer diagnosis.

‘I had to give up office life, because I couldn’t be there and look after my five children at the same time,’ he says.

Masood eventually found a part-time job with a double-glazing company, where he stayed for three or four years until triple bypass heart surgery ended his working life. He remarried six years ago – his wife currently lives abroad – and has five grandchildren.

## Anxiety and agitation

Around eight years ago, a visiting healthcare professional mentioned the results of a brain scan taken after the heart surgery. This had shown that Masood had Alzheimer’s disease and frontotemporal dementia (FTD). FTD is a less common type of dementia that can affect speech, behaviour, problem-solving, planning and the control of emotions.

## Quick read

Masood Qureshi, 63, hopes that sharing his experiences of mixed dementia will raise awareness and help others living with the condition.

Masood, who lives in Stoke-on-Trent, was unexpectedly diagnosed with Alzheimer’s and frontotemporal dementia (FTD) in 2011.

Having accepted his own condition, Masood wants to help make dementia better understood within South Asian communities.

He is also volunteering for Side by Side to support another person with dementia to remain active within their community.



**Hear Masood’s story**  
Listen to this and previous stories at  
[alzheimers.org.uk/podcast](http://alzheimers.org.uk/podcast)



'The diagnosis was accidental – I just didn't know what to think,' says Masood. 'At first I didn't accept it, and then you think of the worst possible scenario.'

'I didn't take it well initially and it took me quite some time to come to terms with it. Because no matter what anybody says about having to be positive, it's still a horrible disease that you know there's no cure for.'

Masood takes comfort that he was at least diagnosed in the earlier stages of the condition, which doesn't appear to have got much worse since.

'I felt I could live well with it and do something about it, which I think is working,' he says. 'However, I don't know if it's going to move all of a sudden, which concerns me.'

Masood has experienced anxiety and depression, and finds himself feeling agitated and worried about things that previously wouldn't have concerned him.

'I don't know whether it's the dementia or whether I've just brought these symptoms on myself, but it's frightening,' he says.

'I have lost some friends – I've not been in contact – because at the back of my mind I was worrying that I might say something that offends them or makes a fool of myself.'

Tasks that used to be second nature have also become harder to accomplish.

'It does concern me,' he says. 'I've cried myself to sleep over it.'

### Speaking out

Masood gets strong practical, financial and emotional support from his very understanding family. He contacted the Society after finding out about us on social media.

'Alzheimer's Society has been very good,' he says. 'They've visited me and advised me on my financial situation. I've been a professional all my working life and don't want to go on benefits really, but I don't understand what I'm entitled to, which is why financially I'm in a mess.'

Masood also credits DEEP, the Dementia Engagement and Empowerment Project, which supports people with dementia to influence the attitudes, services and policies that affect their lives.

'I was a founder member of a DEEP peer support group – the Beth Johnson Foundation – which has helped tremendously,' he says. 'Their support and knowledge have helped me to come out and speak about dementia.'

### Taboo subject

It took a long time for Masood to accept that he had dementia. However, he's now reached a point where he not only acknowledges his condition but wants to do all he can to raise awareness of it.

He's especially focused on a lack of understanding about dementia among South Asian communities.

'I would like to hone in on them and educate them about it,' he says.

'I feel there are a lot of South Asian people living with dementia who are not aware of it or don't understand it. It's a taboo subject with some of them, so I'd like to reach them and give some insight – where to go, who to contact, how to cope. It's quite difficult but I'll have a go.'

Masood has been supported by Alzheimer's Society to give presentations about his experiences of dementia to medical students at Keele University. He has also sat on panels of doctors and patients.

'I think most healthcare professionals don't understand dementia fully, so I want people to know what a person with dementia is going through – our thoughts and feelings, from the heart,' he says.

'The person living with dementia is the expert, so I'm hoping to get the message across.'

Through the Beth Johnson Foundation, Masood was involved in creating a comic-style booklet called There's no bus map for dementia, which saw people with dementia work with artists to

Visit [alheimers.org.uk/share](https://alheimers.org.uk/share) to tell us about your experiences of dementia.

find ways of representing their experiences of living well with the condition.

'People do not stop experiencing things just because they've stopped remembering things,' says Masood, who is a Dementia Friend. 'They are still the same person and can still do a lot of things.'

### A different life

Masood recently volunteered for the Society's Side by Side service,

where he will be supporting another person with dementia to keep doing the activities they love.

'I would like to pass on some of my experience and ways I've adapted to cope with dementia,' he says. 'I can say there is life with dementia, it's just different.'

Masood doesn't find it easy to speak about his experiences but is motivated by the thought that his words might make a difference to

other people who have dementia.

'It's difficult for me to talk about dementia. There's stigma, and it's embarrassing for somebody who's been a professional all his life,' he says.

'It takes a lot of energy, but it also buzzes me up because I've done something that will maybe help someone. I believe somebody will benefit from it. I sincerely hope so.'



Photographs: Mike Frisbee

You can help us support people like Masood to live well with dementia. Please donate at [alzheimers.org.uk/give](https://alzheimers.org.uk/give) or call 0330 333 0804.

For our publications in a range of languages and formats, see [alzheimers.org.uk/accessibleresources](https://alzheimers.org.uk/accessibleresources) or call 0300 303 5933 (local rate).

## Better support, thanks to you

People affected by dementia have helped us develop a new online tool to help others find the information and support they're looking for.

**D**ementia Connect is a service from Alzheimer's Society that provides people affected by dementia with the support they need, when they need it, by phone, online and face to face.

The newest aspect of Dementia Connect is tailored online support, available 24 hours a day. You answer a few simple questions about yourself – or someone you know – to get personalised, relevant information and advice, including the option to request a call from one of our dementia advisers.

### Useful and meaningful

We've done a huge amount of testing and research to ensure the new online service is the best it can be. In addition to surveys and workshops, we've held many sessions where people tried out the service to see how well it worked for them.

'We want Dementia Connect to deliver results that are useful and meaningful for people affected by dementia,' says Rik Williams, who led the testing of the service.

Rik worked closely with colleagues to pinpoint what combinations of helpful information, practical advice and real-life stories would be useful for people in different situations.

The testing involved people with dementia, carers, people worried about their memory and people with accessibility needs, such as with their vision.

'It brought up some themes, such as how much the service could ask of someone who has memory problems and is having to hold the task together in their mind,' says Rik.

'We also addressed problems with the order of information. For example, we moved the request for a person's telephone number to the start of the process, so if they drifted off the website, we could phone them back later.'

### Strategies and solutions

Coral Sutherland, whose mother has Alzheimer's, helped test the new service. She gave feedback on how easy and clear it was to use, whether pages and options appeared in the order in which she expected, and how it all looked.

'I welcomed the chance to be involved in something that's close to my heart,' she says.

We'll be regularly improving Dementia Connect online to make sure that it works for anyone affected by dementia. Coral can already see the service being of huge benefit.

'It's great!' says Coral. 'By asking about the user's situation, the right support and information is ascertained for them.'

'The website's questions may also be the catalyst for opening the user's horizons to strategies and solutions, of which they previously had no knowledge or time to research, contemplate or follow up on.'

Another of the testers, Connie, who has dementia, was made to feel that her contribution was 'valid and worthwhile'.

'The team certainly seem to have discovered something that will benefit everyone who has this debilitating disease,' she says.

'I thank them all for sharing their time and expertise to help. It gives me the heart to carry on!'

**A person affected by dementia testing the service using a tablet in her living room.**



Find our new online support at  
[dementiaconnect.alzheimers.org.uk](https://dementiaconnect.alzheimers.org.uk)

# Why I enjoy languages

We ask people about the different ways they keep healthy and well, whether they have dementia or not. This issue, we hear about language learning.



**Claire Phillips, 54, Cardiff**

I attend Italian classes at Cardiff University. I also go to a U3A conversation group and 'coffee conversation' groups during university holidays. I listen to Italian

music and podcasts, and watch TV programmes like Inspector Montalbano. I try to do something every day.

At first, I did a course online to fit around other commitments. I wanted to do something for myself while caring for my parents, who had dementia. Then I attended an evening course, so that my husband was home if my father needed any help.

It stretches my brain to learn new vocabulary and grammar. The others learning Italian tend to be kindred spirits and there is a lot of laughter.

## **Jeffrey Sutton, Bishop Auckland, with Alzheimer's**

I am fluent in French and Italian, and have reasonable German. I attend an informal Italian conversation class on a regular basis. I wish to not lose my language skills and to acquire new ones.

My alertness has improved and I feel more involved in the community – Alzheimer's can be very isolating.



**Jeannette Meyers, 66, Kent**

I started learning Spanish from scratch. I meet weekly with a group of retired friends and a native speaker, and I'm about to embark on intensive study in the country. I have also started

British Sign Language classes – a challenge I took on as I lost my upper register hearing.

I am a carer for my mother-in-law, who is living with dementia. I arrange replacement care for her when needed, and live-in care when I'm traveling.



**Laura Onslow, 29, London**

I attend weekly Irish classes and practise on Duolingo while commuting. A friend of mine is from Cork but living in Sydney and we sometimes WhatsApp in Irish.

I started learning because of my family connections. My grandfather sacrificed a lot in coming to England – remembering that keeps me motivated when I'm struggling.

My mental health has definitely improved. I wasn't keeping my mind active and was sick of losing concentration and not doing anything after work. It's great to make new friends who have shared interests and cultural connections.

My relationship with my mum has also benefitted, as she talks about her dad and family in Ireland a lot more.



**Shaun Steiner-Goldberg, 49, Brighton**

I use an app to brush up on the Dutch that I started learning a long time ago, but couldn't continue due to lack of classes. I do five to 10

minutes' practice a day, sometimes more, either when I'm alone at home or if I'm travelling.

It makes me concentrate and focus, especially when I'm having to remember verb endings. As it's on my phone, I can do it whenever I have a few minutes spare.

## Stay well

Reduce your chance of developing dementia by 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 healthy and well. Visit [www.nhs.uk/livewell](http://www.nhs.uk/livewell) for health and wellbeing advice for everyone.

# Involving everyone

For a supporter in south Wales, becoming a Dementia Friends Champion has helped her to achieve more than she thought possible.

**L**ouise Barham first got involved with Dementia Friends because she wanted to set up a local dementia-friendly café. Since then, she's also become a Dementia Friends Champion and involved her community in making their area of south Wales a better place to live for people affected by dementia.

'I wanted to learn more about the condition my father had,' says Louise, who lives in Kenfig Hill, a village in the south-west of Bridgend County Borough. 'I thought, if I was ever to have a café, I needed more information.'

## Information sessions

Louise lived too far from her late father to be very involved in his day-to-day care. However, she's determined to change people's perceptions and understanding of dementia in her own community.

'I'm happy to do Dementia Friends information sessions for absolutely anyone! I've been to Mothers' Union meetings and done sessions for our local Designer Outlet, Emmaus, the police, Cynffig Comprehensive School and the top year of Pyle Primary School.

'For the last two years, I've also done "open" sessions at Pyle Life Centre, where we just advertise the session in shops and anyone can just turn up.

'Everyone says they have learned something they didn't know, and they take away something to think about. We also get families coming who want to be able to help a family member who has dementia.'

## Villages Project

Establishing a weekly dementia-friendly café was more of a challenge than Louise expected, but she found the support she needed at Pyle Life Centre, which hosts many community activities.

Louise says it was out of this experience that the Villages Project was born.

'The aim of the Villages Project is to make the surrounding villages – Cefn Cribwr, Kenfig Hill, Pyle, Cornelly and Maudlam – dementia friendly.'

A dementia-friendly community is one where people with dementia are understood, respected and supported, and the project has been raising awareness so that everyone can make a difference.

'I've visited shops and businesses in the area,' says Louise, 'trying to explain a little about dementia and ways they can recognise it and help.'

Louise recognises the importance of involving everybody in the community, including influencers such as local MPs and Welsh Assembly members.

'Dementia isn't going away any time soon,' says Louise. 'Unless we want people to become isolated in their own homes, we must bring dementia into the daylight and ensure everyone has a basic understanding of the condition and how to help.'



Louise (right) with Claire Roberts from Care & Repair at the joint launch of the Villages Project and a similar initiative for nearby Porthcawl.



Find out more about Dementia Friends and how to become a champion at [dementiafriends.org.uk](https://dementiafriends.org.uk)

# Everyone loves cake

A Dementia Friend in Hertfordshire is getting ready to bake a difference again for this year's Cupcake Day.



**P**atsy Weedon is looking forward to another great Cupcake Day after raising over £250 at her cake sale last year.

'It went brilliantly,' says Patsy, a Dementia Friend in Hemel Hempstead. 'I sold all the cakes within a couple of hours, I was so chuffed! It was fun, and all to help fight this terrible condition.'

Patsy speaks from experience – her father was diagnosed with Alzheimer's and vascular dementia in October 2018.

'He went downhill really quickly.

By April 2019, he'd been in hospital four times and the social worker said he needed full-time care.

'It hit my mum and me really hard, as I couldn't face packing him off somewhere. I felt as though I was letting him down.'

However, her dad needed to move into a care home last summer.

'Mum and I had to adjust to it being just us. The money aspect hit us hard too, paying for Dad's care. But he is getting wonderful care.'

## Great opportunity

For Patsy, Cupcake Day meant she could do something positive to make a difference.

'I got involved last year because of my dad, and a close friend who lost his wife to dementia two years ago,' she says.

'My own health means I'm unable to do any charity walks or runs, but I love to bake so it's a great opportunity for me to help.'

Patsy decided to hold a cake sale, and she didn't hold back when it came to baking.

'I baked a large assortment of cupcakes as well as mini Victoria sandwich cakes, loaf cakes and traybakes. I also made a large chocolate gateau, which we raffled.'

Her local Boxmoor Social Club agreed to host the sale a couple of days before Cupcake Day itself (which is fine – you can hold your Cupcake Day event on any date).

'The club allowed me to do it at the weekly bingo evening, which meant more people would be in attendance,' says Patsy.

## More people

Patsy's cake sale is returning this year, and she encourages everybody to hold their own Cupcake Day events.

'People should get involved,' she says. 'Everyone loves cake, and you're raising money and much needed awareness.'

'Try and do your sale at another event, like our club bingo. More people means, hopefully, more money.'

**Sign up for your free fundraising kit at [alzheimers.org.uk/cupcakeday](http://alzheimers.org.uk/cupcakeday) or call 0300 222 5770.**

## Make it matter

Organise your own fundraising event and raise money to support people affected by dementia today.

Make it tasty with a curry night, make it a coffee morning with friends or make it a quiz night – whatever you do, you can make it matter.

**Sign up for your free fundraising pack at [alzheimers.org.uk/makeitmatter](http://alzheimers.org.uk/makeitmatter) or call 0330 333 0804.**



## Become a champion

Dementia Friends Champions give people the information and encouragement they need to make a difference for everyone affected by dementia.

Champions attend an induction and get support when needed to help create dementia-friendly communities everywhere.

**Find out more at [dementiafriends.org.uk](http://dementiafriends.org.uk)**



## Rock for Alzheimer's

Rock and indie fans raised over £7,000 at gigs in Belfast and Derry this February.

Mark Bingham and fellow musicians had already fundraised more than £39,000 since 2013 through the annual Rock for Alzheimer's event at Belfast's Empire Music Hall. Sell-out audiences have supported the event each year enjoying AC/DC tribute band AC?DC, rock cover band The Arms of Venus de Milo and acoustic duo The Foyer Incident. Determined to take the total as close to £50,000 as possible, they decided to hold a second event at the Nerve Centre in Derry this year as well.

Both of Mark's parents had dementia and he won a Dementia Friendly Award for fundraising in 2017.

'It's quite a humbling, but nonetheless uplifting, experience to play to the Rock for Alzheimer's crowd,' he said. 'It's a time for everyone to both reflect and let off some steam, while raising valuable funds to support the charity's valuable work.'



## Capturing nature

A supporter in Lincolnshire has drawn on his passion for nature and photography to raise over £3,000 in the last year.

Roy Briggs, whose wife Joyce has had dementia for 11 years, uses the pictures he takes on his daily walks to help support Alzheimer's Society.

'I sell prints in a local tearoom in aid of the Society,' says Roy, 'but my biggest money-spinner was a wildlife calendar I produced for 2020 that sold 250 copies, raising a total of £1,350.'

'My daily respite time is spent walking in the countryside, getting exercise to keep fit but also snapping wildlife and nature. I have a daily posting of pictures on our local community Facebook site.'

'Although my wife has lost most of her mobility and can no longer accompany me on these walks, I can still show her all the wonderful creatures I've captured most days.'

**Find out how you could raise vital funds – visit [alzheimers.org.uk/fundraise](https://alzheimers.org.uk/fundraise) or call 0330 333 0804.**



## Healthy target smashed

NHS staff in west London surpassed their trust's targets when 80% of them became Dementia Friends by the first week of December last year.

In March 2019, Hounslow and Richmond Community Healthcare NHS Trust committed to 75% of its 1,140 employees becoming Dementia Friends by Christmas. This would include staff working in people's homes as well as in clinics or hospital.

The trust's specialist dementia team – a district nurse and occupational therapist – ran 28 information sessions, while 460 employees signed up online.

Teresa Keegal, the specialist team's district nurse, said, 'The number of referrals to our team has increased since the sessions. These have included some from child health, where a health visitor realised a family was struggling due to caring for their grandmother.'

To maintain this excellent work, Dementia Friends will be provided for all new staff starting at the trust.

# Research priorities

The government has promised a 'Dementia Moonshot' to double dementia research funding. **Laura Mullaney**, Public Affairs Officer, looks at how this should be invested.



**W**ith an extra £800 million promised by the government for dementia research over the next decade, we want to make sure this is invested in ways that have the biggest and most positive impact for people affected by dementia, now and in years to come.

Research is a core part of our mission to unite against dementia. As part of the Public Affairs and Campaigns team, I've been calling on government to Fix Dementia Care by acting on the cost, quality and access issues that people face in getting the support that they need.

As well as finding better treatments and a cure, we want research to help improve care for people with dementia in the here and now. We've highlighted this as a priority in Maximising the 'Dementia Moonshot', our proposal for how government funding should be invested.

We're calling for a new National Network of Excellence for Dementia Care Research, funding for the pioneering UK Dementia Research Institute and support for researchers and clinicians starting out in the field.

We want more research into how people can reduce their risk of dementia, and how they can be inspired to make these changes. There should also be dedicated funds to find technologies that improve dementia diagnosis, management and care.

Visit [alzheimers.org.uk/fix](https://www.alzheimers.org.uk/fix) to join our Fix Dementia Care campaign and influence social care and research investment.

## Could you step up to help us beat dementia sooner?

We're challenging you to walk **850,000** steps within three months – that's the same number of people living with dementia in the UK right now.

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

**Step  
Up**  
for Dementia





## Quick read

Bridget Simmonds, in Chatham, Kent, wants there to be more understanding and respect for people with dementia.

Bridget supports her mum, who has vascular dementia, and her dad, who has Alzheimer's disease.

The family feels abandoned by services who don't keep in touch, while some relatives have shown a lack of empathy.

Bridget is sharing the family's story in the hope that more people talking about dementia will change attitudes.

# Respect due

Bridget Simmonds has felt let down by many people while supporting her parents. **Gareth Bracken** meets a daughter who wants more understanding and respect for people with dementia.

**A**s the only child of parents who both have dementia, Bridget Simmonds feels the strain of supporting them amid some very challenging circumstances.

'There are times I just scream and stomp my feet like a five-year-old,' says Bridget, who lives in Chatham, Kent. 'I've got no idea what the neighbours must think!'

A lack of support from local services and some family members has only added to feelings of isolation, frustration and upset.

'We feel we've been abandoned,' says Bridget, who wants everyone affected by dementia to get the support they need.

## Life and soul

Bridget's mum, who is 82, was diagnosed with vascular dementia around seven years ago.

A passionate gardener, her mum is a former shop and farm worker who also held secretarial roles. In her 50s, she had transient ischaemic attacks (TIAs) – also known as mini strokes – as well as some more serious strokes, which can be associated with vascular dementia. Prior to her diagnosis, she had been experiencing memory problems.

'She was forgetting things. She felt something wasn't right,' says Bridget, a part-time administration assistant, who

previously worked in the legal profession for over 30 years.

There have been changes to her mum's personality and level of independence.

'Mum used to be the life and soul of the party. If there was mischief, she was in it,' says Bridget. 'She's still able to do things and is still in charge at home but, apart from going into the local village for shopping, she isn't able to go out alone.'

## Very upset

Bridget's 84-year old dad, the youngest and last surviving of 11 siblings, worked for the Post Office for 44 years, retiring aged 60 as a transport manager. He was diagnosed with Alzheimer's in February 2019 and he also wears hearing aids.

'It was Mum who noticed changes in Dad,' says Bridget. 'I'd just thought it was his deafness and not knowing how to cope with having to think for himself at home.'

Bridget's dad still volunteers at the local hospital, but he agreed to stop driving last year after becoming flustered in unfamiliar areas.

'Dad knows what's going on and gets very upset because he can't do what he used to,' says Bridget.

'They can laugh about some things to a certain extent, but they aren't the people that they were and that's very hard.'

## Balancing act

Bridget lives with her partner about 45 minutes from her parents. She provides her mum and dad with regular support, including a weekly shopping trip, though they're keen to retain their independence as far as possible. Bridget also takes them out during the week for healthcare appointments, such as to the doctors, dentist or hospital.

'I suppose I am a carer in a way, but they don't like relying on me, so I try and let them sort out their own problems,' she says. 'I have power of attorney as a safety net, but I say to them, "I'm not taking anything away from you."'

There have still been plenty of times when Bridget has needed to step in, particularly with healthcare.

'I've had to do a lot of shouting at the surgery to get things in place,' she says. 'I spend most of my life fighting to get things done. There are times when you don't feel like doing it, but you have to.'

Bridget's parents recently reached their 62nd wedding anniversary, but she also finds herself supporting their relationship with each other.

'Mum gets frustrated at Dad. His deafness – or sometimes selective hearing – makes things very difficult. It causes stress and strain,' she says. 'They just wind each other up! It's difficult for me trying to balance them on my own.'

## Let down

Bridget and her parents feel let down by a lack of support from local services.

‘There are so many people who promise to stay in touch but don’t,’ she says. ‘A hospice came to see us last year about Mum going to one of their groups, but these days she can’t just walk into a room of people she doesn’t know. They were going to come back to us about it but haven’t.’

They have also faced a lack of understanding from certain relatives.

‘When Mum was first diagnosed, some of her family told her, “You’re going doolally,”’ says Bridget. ‘It’s almost like they don’t want to know us or think they’ll catch the dementia.’

Bridget can sometimes feel lonely and isolated, but she’s grateful for some very supportive friends.

‘It’s not easy but you’ve just got to do the best you can,’ she says. ‘Thankfully I know people with experience of dementia who I can bounce things off.’

## Better care

Bridget was concerned when her mum’s GP admitted that she didn’t know enough about vascular dementia.

This is one of the reasons the family has been taking part in Time for Dementia, a programme supported by Alzheimer’s Society. Through this, healthcare students in the south east of England visit people affected by dementia to

better understand the reality of the condition.

‘I’ve told our MP it should be rolled out across the country,’ says Bridget. ‘Show medical people what it’s like to live with dementia day to day and they’ll give better care.’

Our information resources have also been a good source of advice and support.

‘I read the publications and think, “That will be useful,” or, “I hadn’t thought about that,”’ she says.

Both parents have their own This is me document, which records details about a person’s background and preferences. If they go into hospital or receive some other form of professional care, but are having difficulty communicating, staff can use the information to understand and support them.

## Perfectly capable

Bridget wants people like her parents to get the respect they deserve within their communities.

‘Sometimes people talk to me instead of Mum, as if she’s not there, which infuriates her,’ she says. ‘Mum is perfectly capable of having her say, she just might need a bit of time.’

‘These are still people with feelings, maybe even heightened feelings, so don’t ignore them or cut them off.’

Before sharing their story, Bridget was sure to check with her parents, who back her desire to improve awareness.

‘We want others to know that dementia is a problem in society that’s got to be addressed,’ she says. ‘You’re making people more aware of what dementia is and that there are so many types.’

‘By talking about it, you’re getting it out there and getting others to talk about it.’





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

You can help us provide reliable and useful information for people affected by dementia – donate at [alzheimers.org.uk/give](http://alzheimers.org.uk/give) or call 0330 333 0804.

Find support near you by using our dementia directory – see [alzheimers.org.uk/dementiadirectory](http://alzheimers.org.uk/dementiadirectory)



# Inside support

Ed and Judith planning sessions.

## Quick read

Alzheimer's Society has been raising awareness and understanding of dementia at HMP Frankland, a Category A prison in Durham.

Staff and residents have attended Dementia Friends information sessions, and some have become Dementia Friends Champions to deliver their own.

Residents say that they now have more knowledge of dementia and feel more confident in helping others with the condition.

Some residents with memory problems have received one-to-one Society support, including strategies for managing day to day.

With an ageing prison population, dementia is a growing focus for HMP Frankland. **Gareth Bracken** explores how the Society has created greater awareness among staff and residents.

**D**ementia in prisons is an issue that demands attention and action. The number of men aged over 50 in prison is increasing, and prisoners' bodies tend to age more quickly than people on the outside. Although diagnosis rates are low, dementia might actually be more widespread for people residing in prisons.

Gary Towers leads on equalities work at HMP Frankland, a Category A prison in Durham for adult men. He hosts a monthly Grey Matters forum, where older residents can discuss the issues important to them, including dementia.

'Staff and residents can't assist each other if we don't have an understanding of the signs and symptoms of dementia,' he says. 'Armed with this information, we can at least work to make the condition less painful for people.'

Alzheimer's Society has been central in improving awareness of dementia within Frankland, and Dementia Friends has played a key role. People attending a Dementia Friends information session gain knowledge and understanding of the condition. They can then train to become Dementia Friends Champions and spread the message through further sessions.

### More confident

Around three years ago, Judith Hedley, then Dementia Adviser at the Society, began delivering Dementia Friends sessions to staff at Frankland, which then became part of inductions for all new starters.

Her sessions with residents focused on those enrolled in programmes with DART – the Drug and Alcohol Recovery Team. These men have benefited in many ways.

'I didn't know anything about dementia until recently, but I now know more about the effects on different people,' said one resident.

They also felt more able to support others who may have dementia.

'I became more aware of what dementia is about and how to respond to someone with it. It made me feel more confident about dealing with people with dementia,' said another resident.

A third said, 'It opened my eyes to some of the difficulties that people with dementia have. I can now help in the future.'

### Empowered to change

Last year Ed Chivers, Regional Dementia Friends Officer at the Society, held Dementia Friends Champion training for around 20 residents at Frankland, including those who had put themselves forward as DART peer mentors.

'They reflected on the need for a better level of understanding of dementia in Frankland,' says Ed. 'They felt that the prison environment can be a confusing place for everyone, and so may be especially difficult for someone affected by dementia. They also came up with some excellent specific actions.'

In her role as Connecting Communities Lead at Frankland, Kayleigh Mines manages the DART peer mentors.



'When they become Dementia Friends Champions it gives them a sense of belonging – they have a role and feel quite empowered,' she says.

While some of the champions deliver information sessions to fellow residents, many choose to simply talk to others about dementia. This includes rarer types of dementia like Korsakoff's syndrome, a form of alcohol-related brain damage.

'There was a conversation about Korsakoff's,' says Kayleigh. 'Residents might have only seen dementia on TV programmes, so this is raising awareness. I think it's really good.'

Lynn Owen, Frankland's DART Recovery Team Leader, sees great value in involving their peer mentors.

'The mentors have a strong interest in helping other residents,' she says. 'They're also here when we're not, and the residents will open up to them more.'

She feels equally positive about the ongoing impact of Dementia Friends.

'It's been a massive eye-opener – a lot of things stuck in our minds from the sessions,' she says.

'It's powerful to think this could stretch across Frankland and beyond, to other prisons.'

### Same support

Residents worried about their own memory problems have been able to get specific advice from Judith.

'In one of the prisons I've worked in, someone was putting coffee in their kettle, while another was ringing their family 20 times a day and using up all of their phone credit, so I made them posters with instructions and reminders,' she says. 'It's helping people manage day to day.'

Judith notes that Frankland residents should be able to access support, similar to someone out in the community, but her desire to help goes deeper.

'Alzheimer's Society champions the rights of people with dementia and is all about challenging stigma and discrimination, so it doesn't compute with me that these people wouldn't get the same support,' she says. 'It might also lead to a reduction in challenging behaviours.'

'It's small steps that enable people to live well with dementia.'

For our **What is alcohol-related brain damage? (438) factsheet**, see [alzheimers.org.uk/publications](https://www.alzheimers.org.uk/publications) or call **0300 303 5933** (local rate).

Use our online directory to find dementia services near you – go to [alzheimers.org.uk/dementiadirectory](https://www.alzheimers.org.uk/dementiadirectory)

See [dementiafriends.org.uk](https://www.dementiafriends.org.uk) to find out more about Dementia Friends.

# See the person

'This is me' highlights the background and preferences of a person with dementia. Gareth Bracken reports on a hospital making the most of it to provide better care.



## Quick read

'This is me' is a simple leaflet, produced by Alzheimer's Society, used to record details about a person with dementia.

Norfolk and Norwich University Hospital uses 'This is me' to give patients with dementia the best and most appropriate care.

This tool helps staff to provide meaningful activities, build rapport with patients and ensure people are eating and drinking well.

Nikki says 'This is me' helped her mum – who had vascular dementia – regain her identity at the end of her life.

A hospital in Norwich is one of many places using our 'This is me' leaflet to improve care for people with dementia.

'This is me' is a simple way to help make sure that health and social care professionals better understand a person with dementia, whether at home, in hospital or a care home.

It's used to record the person's cultural and family background, their preferences and routines, and important events, people and places from their life.

'It's a window into their likes, dislikes and wishes,' says Liz Yaxley, Dementia Services Manager at Norfolk and Norwich University Hospital.

'It crystallises the things we all need to be aware of and promotes patient safety, dignity and wellbeing.'

Norfolk and Norwich underlines the importance of 'This is me' when training its staff. It also checks how it's being used across the hospital to ensure that relatives and staff are making the most of it.

'Families might see us looking busy and might not feel something is important enough to tell us, but 'This is me' invites them to share that information,' says Liz.

'If we're not aware that someone has taken their tablet with a spoonful of yoghurt for the past two years, even the best staff aren't going to be able to get them to take it with water. It's that level of detail that helps us deliver the best care.'

## Building rapport

Staff at Norwich and Norfolk use 'This is me' to help reduce the anxiety than can be felt by people with dementia in unfamiliar surroundings.

'Wards can be very busy, noisy environments that can cause distressed behaviours,' says Theresa Gall, Assistant Practitioner. "'This is me' can help us build rapport with a patient by providing topics to begin conversations and form connections.

'Talking about their career or if they are animal lovers enables staff to look through photographs with them, or maybe arrange therapy animals to visit wards. It helps see the person beyond the dementia.'

Carla Amaro, Assistant Practitioner, says 'This is me' helps staff support their patients to be as happy and well as possible.

'Having information about their hobbies and pastimes enables personalised activities to be provided to improve their quality of life,' she says. 'Knowing their likes and dislikes can also help with menu choices and to maintain adequate nutrition and hydration.'

## Spreading the message

Jamie Artherton-Howlett, Senior Dementia Support Worker, notes that even seemingly basic information can help.

'Sometimes just knowing what the person likes to be called can help them be more at ease,' he says.

'This is me' can also be used to better understand a person's behaviour and to keep their relatives involved.

'The information we gain means staff can put themselves in a patient's shoes,' says Jamie. 'The emotions of carers are also very important – they like to be heard and "This is me" is really useful for that.'

Norfolk and Norwich is also promoting the use of 'This is me' among people with dementia who are yet to enter hospital.

'We're encouraging them to have it completed beforehand, so if they come to us it's already there,' says Liz.

'Our quality improvement nurses working in care homes are spreading the message, and we're working very closely with Admiral nurses and Alzheimer's Society.

'We want "This is me" to become a regular part of a person's support after a dementia diagnosis.'

### Massive impact

Nikki's mother, who had vascular dementia, spent the last two weeks of her life in Norfolk and Norwich University Hospital. It was here that Nikki filled out 'This is me' and pinned it above the bed, hoping somebody would read it.

'We'd been through a terrible time with Mum and I was broken when I did it,' she says.

Nikki completed the form as if it was her mum writing it, using phrases such as 'I have to...' and 'It makes me feel...'

'There was lots to put in there – Mum lived an amazing life,' she says.

A nurse called Jenny read the leaflet and showed it to other staff on the ward.

'The impact was massive,' says Nikki. 'As soon as they read it, everyone was on board with my mum and gave her very personal care.'

'It helped get her identity back and it gave us back some hope after six years.'

'Thank goodness Alzheimer's Society developed "This is me".'

Nikki highlights the importance of staff taking the time to read a person's 'This is me'.

'Everyone has a story, you just need people to listen,' she says. 'The person is still there – my mum was still human. It's very important not to take that away.'



Visit [alheimers.org.uk/thisisme](https://alheimers.org.uk/thisisme) or call **0300 303 5933** (local rate) for a free copy of 'This is me' – available in English and in bilingual Welsh/English versions.

Connect with others affected by dementia through our online community, Talking Point – see [alheimers.org.uk/talkingpoint](https://alheimers.org.uk/talkingpoint)

For our Hospital care (477) factsheet, go to [alheimers.org.uk/publications](https://alheimers.org.uk/publications) or call **0300 303 5933** (local rate).

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

## Travel insurance

A few months ago, I seem to recall having read some correspondence in Dementia together magazine about travel insurance for people with dementia.

The company who we have used for some years would no longer sell us an annual policy because of my husband's diagnosis.

I can understand this to some extent, but there was no consideration given to the type of dementia, the stage he is currently experiencing, the fact that this was an early diagnosis or the type of holiday, for example with whom we would be holidaying (our supporters).

I wonder if there has been any further feedback from your readers. Have they found a particular insurance company more favourably disposed, or has Alzheimer's Society made any representation about this to the actuaries?

**Ann Palmer**

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

## Society response

We're working with the insurance industry to raise awareness of dementia, and about anti-discrimination law.

Dementia counts as a disability under the Equality Act 2010. Although there are some exceptions for insurers, they need to act reasonably and base their decisions about risk on reasonable and relevant information.

Your insurers should be able to justify their decision in your case, and you can ask them to do that. If you're not happy with their response, you could use their complaints process to make a complaint. If that doesn't resolve matters, then you could complain to the Financial Ombudsman Service – see [www.financial-ombudsman.org.uk](http://www.financial-ombudsman.org.uk) or call **0800 023 4567** (free).

The Financial Conduct Authority, which regulates insurance companies, has said that a new signposting service will be set up, hopefully this summer, to help people who are finding it difficult to obtain travel cover.

We can't recommend specific travel insurance companies, but it's important to shop around because premiums and the level of cover provided can vary widely. Tourism for All may also be able to help – visit [www.tourismforall.org.uk](http://www.tourismforall.org.uk) or call **0845 124 9971** (call charges vary).



## Your turn

Tell us what you think – write to Magazine Editor, Alzheimer's Society, 43–44 Crutched Friars, London EC3N 2AE or email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) Letters for the June/July issue to arrive by 5 May.

Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

## Seen elsewhere...



London Fire Brigade shared a picture on Twitter after more firefighters from Chelsea Fire Station's White Watch became Dementia Friends, at sessions run by Dementia Friends Champion Rebecca Fuller:

🗨 Crews at Chelsea took part in dementia awareness training recently. Another watch signed up as @DementiaFriends. 🗨



When we shared an animation on Facebook highlighting our Fix Dementia Care campaign, Annabel Purnell said why she was adding her support to make the system fairer:

🗨 It's disgusting. Any other illness and care is all paid for – why not dementia? My mum worked as an A&E nurse all her life and now has Alzheimer's. She has to pay for everything. 🗨



When worriedson77, a new Talking Point member, asked for advice about his mum, he was extremely grateful for the response on our online community:

🗨 This forum has been such a goldmine of information and also, to be fair, a bit of a sanity check for myself too. It's hard not to feel alone, especially when you begin to realise that your lifelong confidante in reality can't play the same role that you have relied on. The advice and comfort from here just takes a bit of sting out of the tail, which to me has been invaluable. Thank you. 🗨

## Health and housing: LGBT+ experiences

The Bring Dementia Out programme wants to hear the experiences that LGBT+ people with dementia have had of healthcare and housing provision.

If you're an LGBT+ person living with dementia, or if you support someone who is, then the programme's co-ordinator Claire Days would like to know how your health and housing needs have been met, and what could be improved. They'll draw on this to help make sure that people working in these sectors are better able to support LGBT+ people affected by dementia.

Bring Dementia Out, initially an innovation project led by Alzheimer's Society, is being further developed by range of partners including LGBT Foundation.

Email [claire.days@lgbt.foundation](mailto:claire.days@lgbt.foundation) or call 03453 303030 to find out more.

## Alzheimer's Show: 50% off

Get half-price tickets for this year's Alzheimer's Show at Olympia London on 5–6 June. The event offers practical advice, information, products and services for people affected by dementia.

Use the code ASOC50 for 50% off on-the-day ticket prices of £25 for adults and £17.50 for concessions. People with dementia get free entry, as do under-16s accompanied by an adult.

Book now at [www.alzheimersshow.co.uk](http://www.alzheimersshow.co.uk) or call 01892 723 195.



**'A close friend with dementia is in hospital after a fall. I've looked after him for years, but now I feel excluded from the decisions made about his care.'**

## Something to contribute

If a person can't decide something for themselves, someone involved in their life – and not only family members – could help work out what's best for them.

This is recognised by the Mental Capacity Act 2005 in England and Wales, and by both existing and new laws in Northern Ireland.

Each decision is different, whether it's about which treatment to have or what to have for lunch.

### Whose decision?

If your friend can make a particular decision for himself, he should be supported to do that. He can involve you in this if he chooses.

If there's something he isn't able to make a decision about, then other people will need to decide for him based on what would be in his best interests.

### How can I help?

As his close friend and long-time carer, you probably know things about what's important to him. This doesn't mean decisions should be completely up to you, but you may have a lot of information that's helpful to contribute.

The law in England and Wales says that, if possible, this kind of decision should take into account the views of 'anyone engaged in caring for the person or interested in their welfare'.

In Northern Ireland, those close to the person should be involved where possible.

### What about power of attorney?

If your friend has made a lasting power of attorney (LPA) for health and welfare, then he's appointed someone as an attorney to make decisions about his care if he can't do this himself.

If this isn't you, both his attorney and hospital staff should still try to get your views, since they still have to act in his best interests.

In Northern Ireland, it's not yet possible to make an LPA for health and welfare. However, this will change once a new mental capacity law comes into effect.

### Explain, ask, remind

Explain to hospital staff that you can help if decisions need to be made for your friend. Ask to be included in any 'best interests' discussions or meetings. Remind them about the law if necessary.

Hospitals in England or Wales will have a Patient and Client Liaison Service (PALS) that could help you with this, or with complaining if you don't get anywhere. Ask the hospital about how you can contact their PALS team.

In Northern Ireland, contact the Patient and Client Council – visit [www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net) or call 0800 917 0222.



## Mental capacity law

For our Mental Capacity Act 2005 (460) factsheet, visit [alzheimers.org.uk/publications](http://alzheimers.org.uk/publications) or call 0300 303 5933. For information about the new mental capacity law in Northern Ireland, see [www.health-ni.gov.uk/mca](http://www.health-ni.gov.uk/mca)



**Elin ap Hywel, Aberystwyth,  
aged 58 with Alzheimer's**

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

Not being able to get around as I used to, as I can no longer drive. Also, because I am unable to work, I do not feel that I am contributing.

However, in some ways my life is better because now I have more time to read and meet friends. My son is still at school and has adjusted gradually to my diagnosis; he is very supportive, as is my partner.

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

I would take lots of other people's poetry to read; Welsh poetry both old and new. I would enjoy the solitude to immerse myself in

reading the poetry but would miss my friends. It'd be good if I could take them too!

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

I have a Side by Side volunteer who is a delight. She is full of life and fun. While I feel that I am doing OK at the moment, it is good to know the Society is there.

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

I really like Simon and Garfunkel songs, in particular The Boxer. I find the songs wistful and full of heart. To me, they are poetry put to music.

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

Getting my house in order and more organised would vastly improve my wellbeing. Unfortunately, this is something that I am currently finding rather overwhelming.

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

I do not think I would like to go back in time, after all you would never know who might be there!

But I would love to be able to explore Ireland, it is a place I am drawn to because of the Celtic connections.

**If you have dementia and would like to answer our questions for a future column, email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2.**



Get your regular copy by completing the form on the inside-back cover, visiting [alzheimers.org.uk/subscribe](http://alzheimers.org.uk/subscribe) or calling **0330 333 0804**

40 pages of real-life stories, support, information and ways to get involved. Delivered to your door every two months.

Although there is no fixed subscription fee, we do ask that you make a donation to support the magazine and our vision of a world without dementia.

**Subscribe to  
Dementia together  
magazine today**





A group of people with dementia in Kent try out high-selling products from five ranges in our online shop.

## Popular products

**A**t the fortnightly Peer Support Group Tonbridge, people with dementia meet to share questions and ideas with others who understand what it's like to live with the condition.

They welcomed us to one of their sessions to tell us what they thought of five products from our online shop. These are popular items from different ranges, all designed to help with day-to-day challenges for people affected by dementia.



### Rosebud reminder clock

The Rosebud reminder clock helps people to keep track of time, and of regular or one-off appointments. It comes with a black or white frame, and you can choose what you'd like it to display – for example, whether it shows the precise time or the day of the week and time of day.

There are 20 built-in reminders for meals, appointments and TV programmes, as well as things like checking the front door is locked, feeding the cat, having a cup of tea or taking medication. You can set these to come on at a specific time, either regularly or on a particular date, or you can programme your own. These can include a picture along with a sound and announcement.

Colin said, 'I have one – I got it as a present, I love it!'

He said he uses his as a clock rather than for reminders – its clear display means it's easy to see the time and date.

Group members wanted to know how to set a reminder. This involves using buttons on the back of the clock to select options on the front display, which it was agreed many would need someone to do for them.

People thought it would be useful if a carer, friend or relative could set a reminder remotely with the person's consent, such as through their own phone. Louise, from our online shop, said the manufacturer is looking into this for future models.

Although Trevor was happy to continue using his wall calendar to keep track of appointments, he added, 'The reminder clock could be useful for anyone who is a little bit forgetful – not only for people with dementia.'



### One button radio

The One button radio is a retro-look AM/FM radio that has a magnetic front panel covering most of its controls.

Once the station and volume has been set, the only visible button is a simple on-off switch. This means that, if a person could find a range of buttons and dials difficult or confusing to use, they only need to use the single button on the top of the radio to turn their favourite station on or off.

The look was a bit too retro for Trevor, who said, 'I had a Bose radio. This one looks like it's out of the 1930s!'

Sue, facilitating the group, said, 'It looks nice, but it is big for a radio.'

Trevor thought it would help to have a volume control on the top as well as the on/off button.

'There aren't many times I'd have the radio on and only have it on one volume,' he said. 'It depends on what you're doing, what's playing. Sometimes you've got a louder signal than others, the volume varies a lot.'



### Photo phone

The Amplidect Combi Photo 295 Phone is designed to make it easier to keep in touch with family, friends and other regular contacts. Its desktop phone and cordless handset both have three large, programmable picture buttons, so you only need to press a person's picture to call them.

You can store up to 50 contact numbers on it, it has a built-in answerphone and it's compatible with hearing aids.

People were happy that the number of the person calling comes up on the desktop phone's LCD display, and also that the device is guaranteed for life.

Trevor was also pleasantly surprised to hear that it cost £83.37 with VAT relief.

'That's not a bad price, actually,' he said. 'We've got one virtually the same, but we paid more for it, and that one doesn't have the pictures.'



### Talking time pal

The Talking time pal is a small device that can be kept on a keychain or in a pocket, and which speaks the time and date when you press its button.

When we tried it out, there was a clear announcement that said, 'The time is 12.52pm.' If you press the button a second time, it also tells you the date.

Trevor noted, 'It's definitely loud enough! Maybe not if you're somewhere noisy, like in the pub?'

People were reassured that the small battery is longlasting.



### Sensor light

The 'Get up in the night' sensor light is a bright strip LED that comes on if it's dark and a movement sets off its motion sensor, going off after 30 seconds.

It can be placed alongside a person's bed so that it comes on when they get up at night, or attached to a skirting board, along the bottom of a riser on the stairs and many other places.

Group members were impressed by the simplicity of this product, and the impact it could have in reducing trips and falls.

'That is such a good idea,' said Sue. 'Everyone should have one!'

'And that would be quite a bit of light on the staircase,' added Trevor.

**Without VAT, the Rosebud reminder clock is £69.99, the One button radio is £49.99, the Amplidect Combi Photo 295 Phone is £83.33, the Talking time pal is £11.55 (you don't have to pay VAT if it's bought to be used by a person with dementia or other condition). The 'Get up in the night' sensor light is £16.62.**



See p39 for a chance to win a Rosebud reminder clock.



### Games and activities 10% discount

Get 10% off games, puzzles and sensory products – see [alzheimers.org.uk/shopforactivities](http://alzheimers.org.uk/shopforactivities) and use the code DAW10 at check out.



**'I have mixed dementia and live in a small village in Northumberland. I love the area, but find I'm losing the confidence to get out and about to enjoy it.'**

**It's easy to have your confidence shaken, whether that's caused by other people's lack of understanding about dementia, or from realising that you need more support than before.**

Seeing other people less and giving up enjoyable activities isn't great for anyone. If you have dementia, it's even more important to avoid becoming isolated or feeling less in touch with your friends, family and community.

We support people in many ways (see opposite), including by helping you to stay connected and involved.

## Side by Side

In many parts of the country, Side by Side volunteers support people with dementia to keep on doing the things they enjoy – and to try new things too. It's worth finding out if it's available near you.

When we link you up with a Side by Side volunteer, you can decide what you'd like to do together.

This could be going shopping, watching a rugby match, hillwalking, seeing a show, chatting over tea and cake... whatever brings joy to your life.

Call **0330 333 0804** to find out if you can benefit from Side by Side in your area. If so, we'll look for a volunteer who you'd enjoy seeing, however and wherever you want to spend your time together. Garden centre, swimming pool or library – the place you'd like to be is where we want to be with you.

We all need a chance to have fun and feel good, and that's what Side by Side is all about. You'll both be making a huge difference to each other's lives.

## What else?

There may be other things going on near you that we can put you in touch with that would help you to get out and about, or which provide some other kind of support.

Some of these could be specifically for people affected by dementia, or they might be for anyone, but where the people involved understand the condition and its impact.

Our dementia advisers can help you to find these – call **0333 150 3456** to speak to one – or use our online directory at [alzheimers.org.uk/dementiadirectory](http://alzheimers.org.uk/dementiadirectory)



**Our Dementia Connect service is new, and parts of it might not be available in your area just yet. Call 0333 150 3456 or visit [alzheimers.org.uk/getsupport](http://alzheimers.org.uk/getsupport) to see how we can help you.**



# 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

Our dementia advisers will connect you to the support you need, from one-to-one services to local support groups.

## Contact us today

**0333 150 3456**

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

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

Person living with dementia





Readers tell us what they think about an updated guide for anyone who has a friend or relative with dementia.

# Support for family and friends

**O**ur book this time is a bit of a classic that's recently been updated. Originally published seven years ago, *Dementia: Support for family and friends* is included in the Reading Well Books on Prescription for dementia for libraries. It's now been revised to make sure it's as current as possible.

Caroline Branney, who manages our Dementia Knowledge Centre, says, 'The guide looks at dementia from many points of view, explaining how it affects the person diagnosed, as well as those around them, at home and in residential settings.'

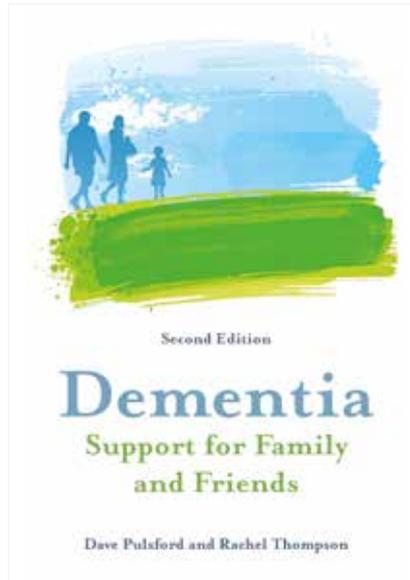
'It is very clearly structured,' says Amanda Carroll, a reader in Lincolnshire who supports older people's mental health.

She says, 'It's written in layman's language but with enough detail to allow a good depth of understanding about what this condition actually is, its causes and how it affects both the person and their family and carers.'

## Readable style

'I really liked the style of the guide,' says Caroline. 'For a textbook, it is well sequenced and individual points are made in clear paragraphs and with lots of bullet points for easy reference.'

'The content follows the progression of dementia, starting with an introduction to living with dementia including an explanation of different types, diagnosis and



description of the disease, key questions and sources of support. The second half of the book then covers the different issues that arise as dementia progresses.'

A reader in Cumbria, A Sturges, says, 'This is a highly readable and very helpful reference book addressing all stages of dementia and its many challenges.'

'My wife has visited people with advanced dementia in a retirement home for many years and she therefore read the chapter on advanced dementia first. The exercise where we are encouraged to close our eyes then open them and imagine you have no memory of what has happened before, the surroundings or the people helped her to understand the anxiety she witnesses on most visits.'

'This book is an excellent resource to equip carers and

others, as each chapter becomes relevant on their relative's or friend's dementia journey.'

## Credible examples

Caroline notes, 'Although there is no specific chapter to represent the voice of people with dementia and their lived experience, people with dementia are included throughout with quotes and scenarios. This does give credibility to the information and makes it easier to relate to.'

John Amos in Hertfordshire says, 'It is very easy to follow and the examples from those living with the illness and/or family or friends do help to illustrate the points raised. It is well indexed and takes the reader through the aspects of dementia from the diagnosis to the end.'

Amanda agrees, 'It covers every aspect from identifying, diagnosing, sources of support, early stage, managing changes as it progresses, challenges in behaviour, considering residential care, advanced stage and end of life.'

## Every step

'The section on eating and drinking is particularly good,' says Caroline, 'as is the information about communication and the emphasis on finding appropriate social and leisure activities.'

'The pages about the "challenges of hospital admission" are very topical and useful, as is the advice about continence

– so important for the person’s wellbeing and sense of dignity.

‘A brief conclusion raises the ongoing debate about the description “suffering from dementia” or “living with dementia” and is a good way to help readers reflect.’

Amanda says, ‘A great, concise book that takes you through every step of the journey, with all the information you’ll need to know.’

John adds, ‘I would suggest that it would be a very useful read for both those who have little knowledge of the progress of the disease and those who are well down the road.’

**Dementia: Support for family and friends (second edition)** by Dave Pulsford and Rachel Thompson (JKP 2019), 304 pages, £9.99, ISBN: 978 1785924378.

## Interesting resources



### Memory Radio

BBC Music Memories includes clips from archive and music-based radio content from the 1940s, 1950s and 1960s. These have been edited into a one-and-a-half hour programme for each decade, accompanied by a printable activity guide.

Visit [www.bbc.co.uk/musicmemories](http://www.bbc.co.uk/musicmemories) and click on ‘Memory Radio’.

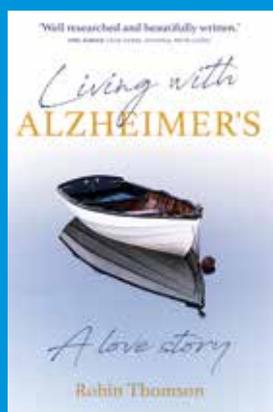


### Young carers’ rights

Know your rights: Support for young carers and young adult carers in England is a free 24-page guide from Carers Trust. Informed by real-life experiences, it looks at different types of assessment and what to expect afterwards.

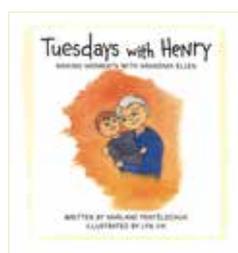
See [www.carers.org/knowyourrights](http://www.carers.org/knowyourrights) or call 0300 772 9600.

## Your turn



For the next issue, we invite you to read *Living with Alzheimer’s: A love story*, by Robin Thomson (Instant Apostle 2020), 192 pages, £8.99, ISBN: 978 1912726 196.

Let us know what you think about this memoir from a carer whose wife had dementia. Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2 by 7 May so we can share it in our next issue.



### Tuesdays with Henry

A simple story for young children about involving them when visiting someone who has dementia, from a former teacher whose mother had dementia. It includes a section for parents to help focus on making ‘moments’ rather than memories.

**Tuesdays with Henry: Making moments with Grandma Ellen**, by Marlane Pentelechuk (FriesenPress, 2019), 48 pages, £8.49, ISBN: 978 1525544606.



## Book giveaway

We have five copies of *Living with Alzheimer’s: A love story* to give away – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2 by 17 April quoting ‘Living’ for a chance to win one (see p39 for terms and conditions).



Talking Point members share how they've dealt with things discouraging a person with dementia from getting out and about.

## Barriers to going out

'My dad wasn't keen to walk as it became more difficult for him, but a wheeled walker helped with his mobility. I decided on getting the walker after seeing how fast he could disappear with a supermarket trolley!

'Later on, as his confidence and mobility decreased, I found I could get him out for a short walk if lunch was included in the deal. My waistline suffered though... I'm still working on that!' **Bunpoots**

'For my aged mother, in her own words, "I will leave this house in a box when they carry me out!"

'No matter how much I cajole, she's not going to socialise – so I have sadly accepted that and I'm now reconciled to her isolation.

'That's why the carers going in four times a day, and the cleaner, window cleaner and gardener all doing a couple of hours once a week or fortnight, are how I can feel comfortable with her choices. Sadly, she finds processing conversations hard as she declines but that's fluctuating from day to day.

'It saddens me but I have done my very best. On the rare occasions I winkle her out, it now takes two people. The decline is obvious and that leads to my heart breaking all over again.' **DesperateofDevon**

'My partner does get a bit anxious about going out sometimes. Cars getting too close or playing loud music scare her easily. So far, a bit of gentle reassurance and humour get her out two or three times a week, but I know it will get harder.

'For mobility issues, which are also related to arthritis, she accepted a wheelchair early last year. That makes life easier, as even getting on and off of chairs at cafés or restaurants was getting hard. She is slowly losing confidence getting in and out of the car and on and off the chair, so patience is needed. Once she is on the chair though, life is so much easier for both of us.' **nae sporran**

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

We asked this question before coronavirus (COVID-19) became an issue – remember to follow guidance to avoid catching and spreading it, see [www.nhs.uk](http://www.nhs.uk)



Photograph: Freemages.com/mikael cronhamm

### Next issue

What advice would you give about coping with the impact of coronavirus if you have dementia or support someone who does? Email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or write to the address on p2.



## Books and stories

**M**any people with dementia continue to read for pleasure, whether novels, short stories or non-fiction. A person may already know what they'd like to read next, but it could be worth talking about books they'd like to read again, or things they always meant to read but never got around to.

If a person's finding it harder to keep track of longer pieces of writing, they might prefer shorter or more episodic stories. Anthologies and other collections could be a good source of these. Some people like reading together.

A visit to a bookshop or public library could be enjoyable in itself, and books can be bought and reserved online too.

Some people find ebooks useful, since using devices such as a Kindle means that you can adjust the size and appearance of text.

If a person enjoys listening to stories, libraries and bookshops will usually also have audiobooks and large print. Many are also available from RNIB – visit [www.rnib.org.uk/reading-services](http://www.rnib.org.uk/reading-services) or call 0303 123 9999.

You can also get a huge range of audiobooks online from providers such as [Audible.co.uk](http://Audible.co.uk), and through 'Audiobooks' categories on Google Play or BBC Sounds – including episodes of radio favourites such as Book at Bedtime.

Visit [shop.alzheimers.org.uk](http://shop.alzheimers.org.uk) or call 0300 124 0900 (local rate) for many helpful products, including our guide **Taking part: activities for people with dementia (£10 plus postage)**.

## Easy Read factsheets

Our Easy Read factsheets are for anyone with learning disabilities, to help them understand the issues around dementia.

They break information down to make it more manageable by using images and plain language.



Order your free copies now by calling **0300 303 5933** or emailing [orders@alzheimers.org.uk](mailto:orders@alzheimers.org.uk)

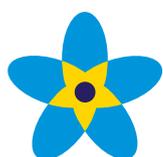
- Easy Read: What is dementia? (ER1)
- Easy Read: Helping a person with dementia (ER2)



Over 3 million  
people have become  
Dementia Friends

Will you join them?

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



**Dementia  
Friends**

An Alzheimer's Society initiative



**Alzheimer's  
Society**

United  
Against  
Dementia

## Reminder clock



Ravencourt, which produces a range of daily living aids, has given us a Rosebud reminder clock for one winner and Talking time pals for two runners-up, drawn from correct entries received by 10 May.

**Q:** In 1094, the great polymath and genius Su Song completed his 40-foot-tall water-powered astronomical clock tower in:

- A. Kaifeng.
- B. Norwich.
- C. Athens.

## Games and activities

Active Minds is giving two 35-piece jigsaw puzzles (Cat's Whiskers and Bathing Birds), Snakes and Ladders/Ludo and a Natural World Aquapaint set for four winners, drawn from correct entries received by 3 May.

**Q:** Senet, the oldest known board game, has been found in tombs dating as far back as the 4th century BCE in:

- A. England.
- B. Italy.
- C. Egypt.

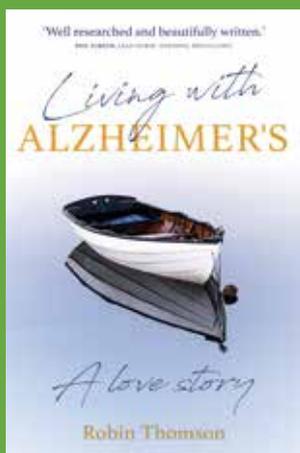


Send us your answers with your name and address – email [magazine@alzheimers.org.uk](mailto:magazine@alzheimers.org.uk) or post to the address on p2.

**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 *Living with Alzheimer's: A love story*, by Robin Thomson.



## Menswear competition

G Gregory in Lancashire won a men's pyjama set, D McKillen in County Antrim a belt and R Smith in Surrey non-slip socks. Answer: The statement we made up was, 'The cat's pyjamas only go down as far as the bee's knees.'

## Wedding favours competition

Sets of 10 gold pin badges were won by J Nicholls in Wiltshire, E Kenny in Merseyside and S Sellens in East Sussex. Answer: The untrue statement was, 'If you support us on your wedding day, we will accompany you on your honeymoon.'

## Book giveaway

The five readers who each won a copy of *Dementia: Support for family and friends* (second edition) by Dave Pulsford and Rachel Thompson, were J Anderson and A Sturges in Cumbria, A Carroll in Lincolnshire, L Close in Hampshire and J Amos in Hertfordshire.

February/March winners and answers



# Rise to the occasion and bake to beat dementia

Sign up for your free fundraising kit at [alzheimers.org.uk/cupcakeday](https://alzheimers.org.uk/cupcakeday)

0300 222 5770

[cupcakeday@alzheimers.org.uk](mailto:cupcakeday@alzheimers.org.uk)



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

