

Dementia together

February/March 2020
Alzheimer's Society's magazine

More than medicine

Social prescribing

Reading interest

Montessori approach



Dispelling myths

Making a difference

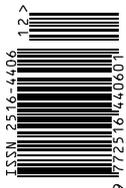
Also in this issue

Keep the pressure on
Dementia Connect
Menswear range



It's all of us

Everyone should know





Welcome

As we start the new decade, it's clearer than ever that the world doesn't stand still, and neither do we.

Jeremy Hughes is stepping down after more than a decade as our Chief Executive Officer (CEO). Alzheimer's Society has travelled an incredible distance during that time – a journey we've only been able to make thanks to the support of people like you.

Of course, there's so much more to be done to achieve a world without dementia, and to transform the lives of people affected by it. Kate Lee, our new CEO from April (see p7), brings a wealth of experience to lead us as we meet the challenges ahead.

As usual, we've got a treasure trove of real-life stories and ideas for you in the magazine – please make sure that your family, friends and colleagues know how to subscribe (see below).

We're always keen to hear your comments and suggestions about the magazine, so use our contact details below to share your thoughts and ideas.

Danny Ratnaik
Magazine Editor

Questions about dementia? See p33.

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

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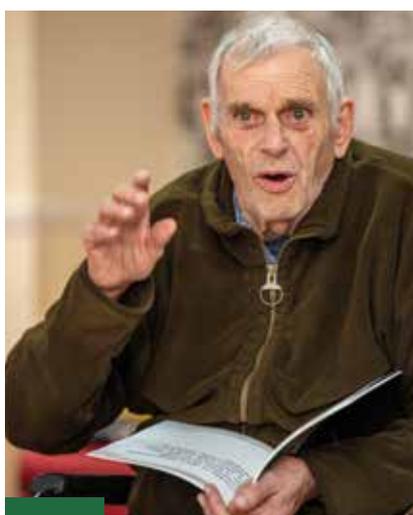
See alzheimers.org.uk/magazine for online articles, PDFs and podcasts.



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Keep the pressure on

Alzheimer's Society is calling on the new government to make a significant and immediate investment into social care.

After our Fix Dementia Care campaign demanded action, the Conservative election manifesto and Queen's Speech included several commitments on social care and dementia, including an additional £1 billion a year in social care funding.

However, ahead of an expected March budget, our evidence shows that this isn't enough to maintain the current system or end the heartbreak we see across the country. Families continue to battle an extortionate and ineffective social care system.

We will be doing everything we can to hold the government to its promises. It's said that cross-party talks on a long-term solution to the social care crisis will begin within its first 100 days, and that no one should have to sell their home to pay for dementia care.

The Prime Minister has pledged to double dementia research funding to £1.6 billion over the next 10 years. We have already sent our recommendations about how this should be invested into care, cure and prevention.

Help us keep the pressure on the new government – visit alheimers.org.uk/fixdementiacare

A very elfy total

This year's Elf Day has raised a fantastic £355,000 and counting! A huge thank you to everyone who unleashed their inner elf to help beat dementia.



Trek26 is back for 2020!

Help us stop dementia in its tracks by joining us at a Trek26 event this year. There are six stunning locations to choose from, each with the option of walking 13 or 26 miles.

We've got a trek that'll take your fancy, whether it takes in Dartmoor – our brand new route – the historic Hadrian's Wall or beautiful Ullswater in the Lake District. Add to these an unbreakable team spirit and a glass of fizz at the finish line – we think it's a winner!

Sign up at alheimers.org.uk/trek26 or call 0330 333 0804.

A plan for personalised care

People affected by dementia have been sharing their ideas to help make dementia care suit each person's needs and preferences.

The Dementia Choices Action Network (DCan) – a collaboration to make dementia care in England as personalised as possible – recently held its first full Assembly meeting. The theme was Developing a vision and a plan for personalised dementia care.

People with dementia joined social care professionals, healthcare commissioners, the Society and others to come up with actions, and ideas about how they could work together to make this happen.

Email dementiachoices@alheimers.org.uk to find out more about DCan and future events.

Get ready to GLOW

Walk towards a world without dementia this spring at GLOW, Memory Walk's brand-new nighttime event.

Whether you're walking to remember a loved one or simply wish to spend time with family and friends, join us for an evening like no other at locations across England and Northern Ireland between Friday 6 March and Saturday 21 March.

Each event starts from 6.30pm and ranges in length from 4.5–6km, catering for all ages and abilities.

Take in the atmosphere, grab your glowsticks and get ready to walk alongside hundreds of others as you make a real difference to those affected by dementia.

You can also be part of this unforgettable experience by volunteering with us – cheer at a marshal point, sell merchandise or congratulate walkers with a finish line medal.

Find out more at memorywalk.org.uk/glow or call 0300 330 5452.

Easy Read factsheets

We've updated our information for people with a learning disability. Our two Easy Read factsheets explain about dementia and how to support someone with the condition using simple sentences and photos in a clear layout.

A group of people with learning disabilities in Belfast, including Dementia Friendly Communities Champions (see p14), reviewed the information in the factsheets and how it is presented, as well as appearing in photos.

Easy Read factsheets What is dementia? (ER1) and Helping a person with dementia (ER2) are available in print and online.

Visit alzheimers.org.uk/easy-read-factsheets or call 0300 303 5933 (local rate).

Girlguiding activity packs

Alzheimer's Society has teamed up with Girlguiding in our latest initiative to help create a dementia-friendly generation.

Activity packs created by us are being used across the four age sections of Girlguiding. They will raise awareness of dementia, make new Dementia Friends and inspire young women to take action in their community.

'As the number of people living with dementia increases, more and more young people are likely to be affected. It's vital that we continue to raise awareness among younger generations,' said Sophie Woods, Senior Youth Engagement Officer at the Society.

For our resources for schools and youth groups, see alzheimers.org.uk/youngpeople

William Hill partnership targets £2 million

A partnership between Alzheimer's Society and William Hill, launched last year, is already raising funds and awareness in the fight against dementia.

The William Hill Foundation has committed to raising £2 million over three years, split equally between supporting local Society services and funding research into dementia.

A Forget Me Not Quiz night raised over £85,000, with support from celebrities including comedian Hugh Dennis and former sports stars Robbie Savage and Sir AP McCoy. Attendees were entranced by a speech from Peter Middleton about his experiences of living with dementia. William Hill staff have also been raising money by taking part in RideLondon, Memory Walk and other events.

William Hill plans for all of its staff to become Dementia Friends, and will continue to use its public profile to raise awareness of dementia.

Since I started at Alzheimer's Society in 2009, we've made some great progress thanks to our amazing volunteers, employees and researchers. This spring, I hand over to a new Chief Executive Officer – Kate Lee.

Dementia is now talked about more than ever before and over 3 million of you are Dementia Friends. More people get a timely diagnosis and are connected to support from the Society and others. But around a third still don't get diagnosed, and some are still afraid to speak out about dementia.

We're rolling out our Dementia Connect service to provide better support to everyone, and our wonderful Side by Side volunteers are a key part of this. However, unlike other conditions where costs are met on the NHS, families bear the financial burden of dementia care and the government has yet to end this injustice.

We have transformed the future through our research, and the UK Dementia Research Institute has quickly become a global leader while our innovation programmes improve care and support today.

None of these achievements are possible without our donors – thank you for your generosity. We need to do much more in the new decade and that will need funds, for example through more regular giving, more Memory Walkers and more people deciding to leave a legacy to us.

It's been a privilege to lead the Society and I look forward to continuing to support as a Dementia Friends Champion, volunteer and donor, as well as through the World Dementia Council.

Jeremy Hughes
Chief Executive Officer



Good if used well

Recent media reports announced that an existing drug could help people with dementia who are experiencing psychosis. This could benefit many people, though it's essential to make sure that drugs are used in the right way.

Psychosis can cause a person with dementia to perceive or interpret things differently, perhaps with hallucinations or delusions. This can affect their behaviour in ways that are distressing for them and the people around them.

A trial testing the antipsychotic drug pimavanserin in people with dementia has shown so much promise that the researchers ended it early. Pimavanserin is already used by people with Parkinson's, and regulators will now consider its use by those with dementia.

Antipsychotics can be effective in treating psychosis in people with dementia. However, they are also sometimes prescribed to people who are experiencing behavioural or psychological symptoms of dementia where there are better alternatives that have fewer serious side effects.

James Pickett, Head of Research at Alzheimer's Society said, 'Although well tolerated in this study, we know that antipsychotics can be prescribed inappropriately for people with dementia, so robust guidance and regulation on monitoring and review of the use of these drugs is essential.'

Research has shown that training health and social care professionals in dementia and person-centred care reduces the inappropriate use of antipsychotics, also reducing the risk from harmful side effects and improving people's quality of life.

Find out more about our research at [alzheimers.org.uk/research](https://www.alzheimers.org.uk/research)

Emergency services guide

A new Alzheimer's Society guide for emergency services explains how dementia can affect a person's experiences and what those services can do to best support them.

Created with involvement from the police, fire service and ambulance service, our Dementia-friendly emergency services guide also offers information on supporting employees affected by dementia.

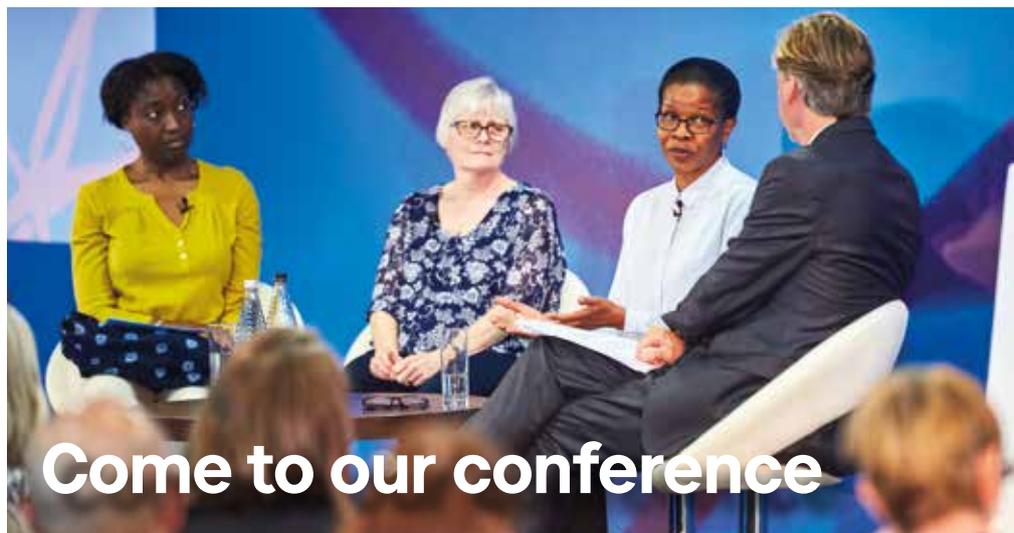
To download the guide, visit [alzheimers.org.uk/emergencyservices](https://www.alzheimers.org.uk/emergencyservices)

1 Million Minutes

Viewers of Good Morning Britain have been pledging to volunteer for Alzheimer's Society as part of the ITV show's 1 Million Minutes campaign.

We were one of six charity partners in the December campaign, which raised awareness of loneliness in the UK. People who chose us were invited to become either a Dementia Friend, Dementia Friends Champion or Side by Side volunteer.

We were represented on the show many times throughout the campaign, including by Ambassadors Scott Mitchell and his wife Dame Barbara Windsor – who has dementia – sending Christmas greetings to viewers.



Come to our conference

Alzheimer's Society Annual Conference 2020 will be built around people's personal and professional experiences of dementia, so join us and have your say.

The two-day event, in London on 18–19 May, will present the views and stories of people with dementia and carers. There will also be expert speakers from across research, policy, care, government and community groups.

Book your place at [alzheimers.org.uk/conference](https://www.alzheimers.org.uk/conference) using the code DEMENTOGETHER10 for a 10% discount.

Musical Map

As part of Music for Dementia 2020's campaign to make music more accessible for people living with dementia, the organisation has launched a Musical Map for Dementia, highlighting dementia-friendly musical activities and services nationwide.

See what's available in your area at www.mfd2020.co.uk

Our new CEO: Kate Lee

Following Jeremy Hughes's announcement that he is stepping down after more than 10 years as our Chief Executive Officer (CEO), Kate Lee has been appointed to take up the reins in April.

Kate comes to Alzheimer's Society from the young people's cancer charity CLIC Sargent, where she has been CEO for four years. She previously headed the Myton Hospices, a large palliative care charity in Coventry and Warwickshire, where she worked with many people with dementia and their families.

Kate's mother was diagnosed with vascular dementia in 2006 and has lived independently until recently with our and others' support.

'I am delighted, but also privileged, to have this incredible opportunity to lead Alzheimer's Society in its next chapter,' said Kate.

'Having had first-hand experience of the devastation that a dementia diagnosis can have on a family, along with the amazing professionalism, warmth and understanding the Society's team of committed volunteers and staff bring to that heartbreak, growing the impact of this organisation is truly a dream job for me.'

Solving challenges: Your ideas

Alzheimer's Society is finding new ways to involve more people in solving the many challenges that dementia can bring, including through our online Innovation Hub.

A range of individuals and organisations took part in our Bring Dementia Out project, looking at how to improve support for lesbian, gay, bisexual and trans (LGBT+) people affected by dementia. This work is being continued by our partners including LGBT Foundation, which has recruited a Bring Dementia Out Co-ordinator to build on it further.

In another project, nearly 150 people, including RAF personnel, explored ways to support people serving in the airforce with caring for a person with dementia from a distance. This led to two solutions that will be introduced this year.

Our Innovation Hub website means that anyone can get involved in sharing and commenting on ideas that will make a difference to people's lives. This has included ways to improve the hospital experiences of people affected by dementia, and there will be many more topics in future.

The Innovation Hub will be looking for your ideas later this year – visit innovationhub.alzheimers.org.uk

Northern Ireland award

Alzheimer's Society has won an award for our work on dementia and learning disabilities in Northern Ireland.

The Society won the Engaging for Change category at the World Health Organization (WHO) Belfast Healthy City Awards, which celebrate projects that promote health and wellbeing.

The award was accepted by Tracy Smyth, a Dementia Support Worker who has been working with people with learning disabilities to make Belfast more dementia friendly and help those with learning disabilities better understand dementia.

Don't miss...

Jean loves seeing Side by Side volunteer Elaine because, 'We're on the same wavelength.' See p12.

Finding puzzles and games that you enjoy could help you to stay well. See p13.

Quit for a Bit to raise funds for Alzheimer's Society this March. See p17.

People with dementia can benefit from 'prescribed' activities. See p22.

Partially sighted people can read or listen to our information in various ways. See p32.



Hear Gordon's story
Listen to this and previous stories
at alzheimers.org.uk/podcast

It's all of us

Gordon Lambert is doing everything he can to help himself to live well with dementia. **Gareth Bracken** meets a man who wants people to understand that dementia is everyone's business.

Gordon Lambert endured a difficult upbringing in Guyana on the northern coast of South America.

'My mum said to me that if I don't work, I don't eat,' he says. 'I would clean houses and yards, repair fences, pick up bottles to sell. She would get the money but I would get something to eat.'

After years of abuse, a teenage Gordon ran away from home to start a new life in England. Many decades later, his latest challenge is a diagnosis of dementia. Once again, he's taking decisive action to improve his situation as best he can.

Escaping abuse

'My mum never bought me anything. I had to look after myself – that was my life,' recalls Gordon, now 81.

'When my school asked why I wasn't going there, she would send me for maybe two weeks. But that meant I wasn't working, so I didn't get anything to eat.'

'I'd see if I could find money on the road to buy food and drink. Sometimes I'd even look in dustbins to see if I'd get anything to eat.'

He also experienced physical abuse.

'Two or three times a week I'd get licks,' he says. 'She's beating me saying, "I'm gonna kill you!"'

'She never actually told me why she did it, although she would say, "You're just like your

father.'" But when I was older and found out who my father was, he seemed to be the nicest person you could find.'

Gordon worked at different times in a sawmill, bakery and grocery shop. Eventually, aged around 15, he decided to escape his mother by leaving the country, which was still called British Guiana at the time.

While attempting to get a passport, he discovered that he was listed on official records under a different surname to the rest of his family. This led him to believe that the woman he'd always thought was his mother might not have been after all.

Having said goodbye to his father, Gordon prepared for a fresh start in a new land.

'I'd worked with a gentleman from Brazil, who had a plantation there where I could get a job,' he recalls.

'The last Sunday of every month, the ferry leaves Georgetown for Brazil. He arranged for me to meet him. He's gonna pay my passage. But when I got to the port, the ferry wasn't there. It would always leave at 9.15am – this particular morning it had left at 8.45!'

Change of plan

A deflated Gordon was bound for home when he was offered an unexpected opportunity.

'This bloke said he was going to stow away on a boat to

England and wanted someone to go with him,' he says.

Although they were discovered on board, the water was too rough to transfer the stowaways to another boat headed back to port. Instead, the captain put them to work on the ship to pay for their trip.

'The journey only took four or five days, so they reckoned we didn't do enough work,' says Gordon. 'They put us in a boy's prison for four weeks to make up the difference.'

Quick read

Gordon Lambert, 81, is striving to stay sharp following his diagnosis with vascular dementia a few years ago.

Gordon, who grew up in Guyana and now lives in east London, has continued doing his usual tasks alongside new activities.

Alzheimer's Society put him in touch with local support and activities, such as Singing for the Brain and a Focus on Dementia Network group.

Gordon wants greater understanding and compassion for people with dementia.

After initially struggling to get a job because of a lack of paperwork, Gordon eventually worked at a car spray-painting business for just over a year, before spending the next 20 at a furniture factory. He was then a security guard for shops, offices and private clients.

Now in east London, Gordon has been married to Mary – who’s originally from the Caribbean island of Monserrat – for over 60 years. They have five children and five grandchildren.

Staying sharp

Gordon was diagnosed with vascular dementia around three years ago after some puzzling experiences.

‘I’d walk to the toilet but then couldn’t remember why I went there,’ he says. ‘That was the main reason I went to the doctor.’

‘A couple of times, when I was coming in from outside, I’d pass where I’m living. I couldn’t understand it. I kept thinking, “I don’t know what’s wrong.”’

Gordon can also struggle with reading.

‘I see the word, know what it is, but yet call it something else,’ he says.

On the advice of healthcare professionals, Gordon has been finding ways to keep his mind active.

‘They said I mustn’t get into myself too much. I must do things that I always do,’ he says. ‘Painting the kitchen, paying bills, going shopping – it keeps you sharp.’

‘When I’m out, I keep looking at car number plates to give myself something to think about. When I’m indoors I play with playing cards. I find that what I’m doing is helping.’

Faith and family

Gordon strives to remain upbeat about his situation but admits this isn’t always possible.

‘I try not to think about dementia too much and I don’t want it to get me down too much, but it’s a challenge to stay positive,’ he says. ‘Sometimes I sit at the table and tears come to my eyes, because I think of all the things I would like to do and places I’d like to go but can’t.’

As a churchgoer, Gordon credits his faith with helping him navigate some tough times.

‘It’s very important to me,’ he says. ‘If it wasn’t for my faith, I don’t think I’d be able to carry on.’

He receives good support from his family, including Mary, though she faces challenges of her own with mobility.

‘We support each other,’ says Gordon. ‘She cares for me and I care for her – it’s more or less equal.’

Alzheimer’s Society has put Gordon in touch with local support and activities that have also been beneficial. He loves going to his nearest Singing for the Brain group, where he enjoys the atmosphere. He’s even bought his own wooden percussion instrument and he takes it along to every session.

‘I haven’t a clue what it’s called, but they all love it!’ he laughs.

He also attends a Focus on Dementia Network group, where people affected by dementia have their say and influence the work of the Society and other organisations.

‘We’ve spoken about public transport and buses. Anything that can help a person with dementia, we discuss,’ says Gordon.

Anyone affected

Gordon was one of four Hackney residents who appeared on posters during last year’s Black

Gordon contributing to Black History Month with (from left) Kim Jones, her daughter Shontell Jonas and Harry Johnson, Dementia Friendly Communities Officer at the Society.



History Month. Organised by Dementia-Friendly Hackney – a community group co-ordinated by Alzheimer’s Society – the posters underlined the kinds of rich life histories that every person with dementia has.

‘That was great,’ says Gordon, who also shared his experiences through the Society’s website.

‘I enjoy sharing my story,’ he says. ‘I hope people read about what I’ve been through as a child and then treat their children in a better way.’

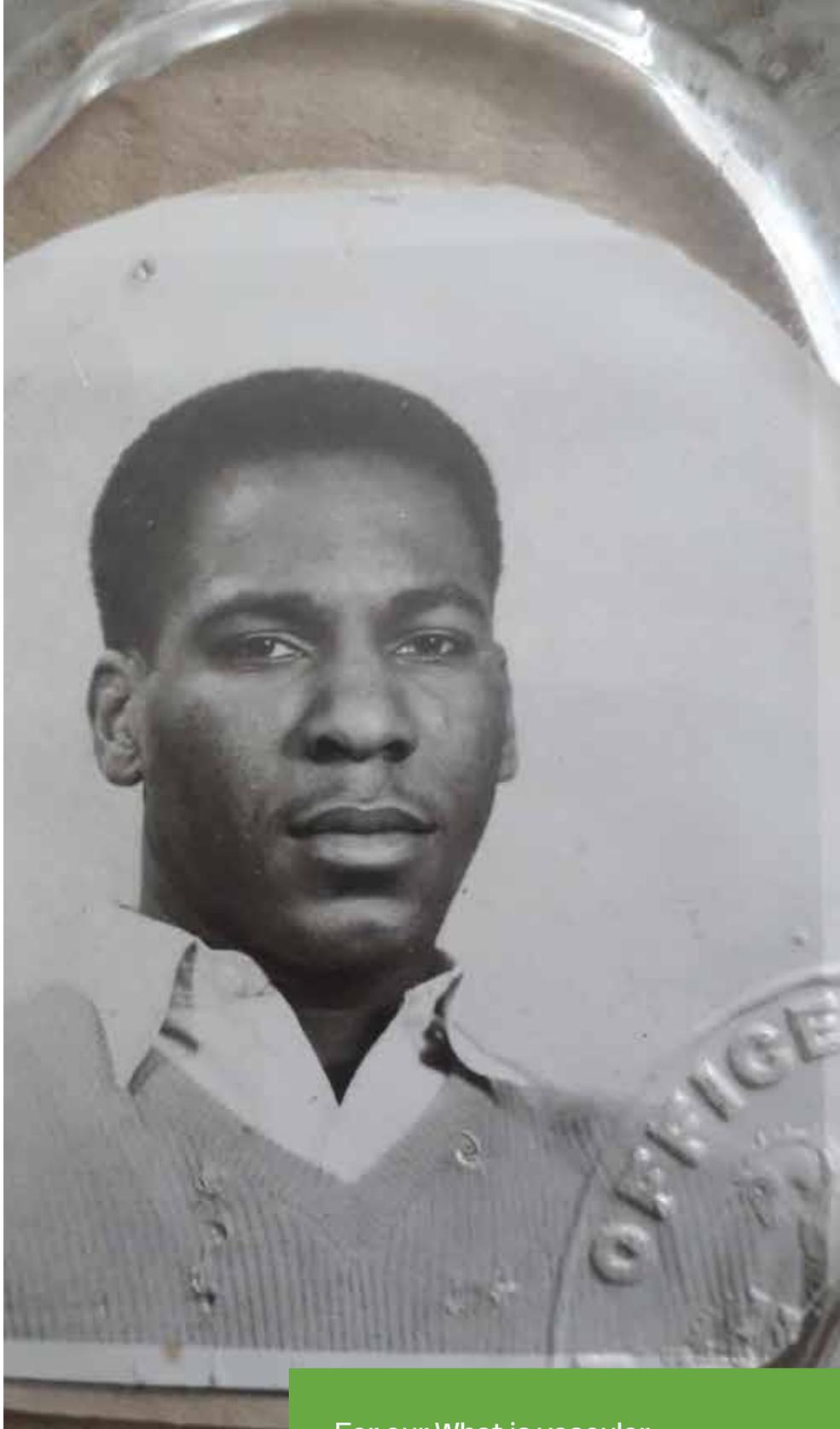
When it comes to dementia, Gordon has mixed opinions on how people with the condition are treated.

‘I think awareness might be getting a bit better, but there are some people who don’t care,’ he says.

‘People are very helpful on the bus, but one time I fell outside and people were just looking at me and walking past. I suppose they thought I was drunk. I actually started crying. There’s no way I would pass somebody and not try to find out what’s wrong with them.’

Gordon wants others to realise the true impact of dementia.

‘More people should know about it – it’s something that anybody can get,’ he says. ‘People should know that dementia isn’t only affecting a particular type of person or group, it’s all of us.’



You can help us put more people in touch with local services – visit alzheimers.org.uk/give or call **0330 333 0804** to donate.

For our What is vascular dementia? (402) factsheet, see alzheimers.org.uk/publications or call **0300 303 5933** (local rate).

Find dementia services near you by using our dementia directory – see alzheimers.org.uk/dementiadirectory

On the same wavelength

A Welsh speaker with dementia is thriving on volunteer support through Dementia Connect.

Dementia Connect, the Society's new personalised support service, means people affected by dementia are only one click or call away from the help they need. Our dementia advisers can support people directly by phone or face to face, and connect them to online support.

'I can provide tailored support to the person who has dementia or is going through the diagnosis process, and their families and friends,' says Caroline Smith, Dementia Adviser in Ammanford, south Wales.

'I can offer information, strategies and signposting, or just a listening ear.'

Dementia Connect, which is becoming available in an increasing number of areas, provides the right support at the right time as a person's needs change.

'The keeping in touch part of the service – where a person receives a telephone call every few months to see how they are – has been a great success,' says Caroline. 'People find it reassuring to know that they haven't been forgotten.'

Closer relationship

One of the people with dementia supported by Caroline is Jean Jones, a former librarian who lives on the Cardigan Bay coast.

Jean wanted to remain as active as possible, so Caroline referred her to our Side by Side service – a key part of Dementia Connect – where volunteers support people with dementia to remain part of their community.

Since mid-2018, Jean has been meeting with volunteer Elaine Davies (pictured) for a couple of hours a week. They go on walks, shopping trips and visits to local places of interest.

Elaine and Jean are bilingual and have struck up a bond both in and through Welsh.

'We had a local poet in the village years back whose wife used to bring me some of his poems, which I would recite and record for her in Welsh,' says Jean.

'Elaine found me a copy of one of his books, so we've been going through a few of the old poems together. It's been lovely remembering the words that I learned years back.'

'We have lots of good chats and I love telling her some of the stories I remember – some funny, some sad.'

'I think us both being Welsh speakers has helped make our relationship closer. We're on the same wavelength and I'd miss her if she didn't come.'

For Elaine, seeing Jean has become like visiting a friend.

'She's a delightful woman who I've learned a lot from,' says Elaine.

'There's a certain sense of satisfaction that you perhaps brighten up her week and enable her to do things that she wouldn't otherwise be able to do.'

Back in control

Debbie Williams, the Side by Side Co-ordinator who brought Jean and Elaine together, says the service is helping people with dementia feel less isolated.

'It gives them some independence,' she says. 'Many had been unable to continue doing the activities they once enjoyed, so it gives them back a bit of control in their lives.'

'For some it's the highlight of their week.'

Find volunteering opportunities in your area, see alzheimers.org.uk/volunteer or call 0300 222 5706 (local rate).



As Dementia Connect is new, parts of the service may not be available in your area just yet.

Call 0333 150 3456 or visit alzheimers.org.uk/getsupport to see how we can help you.

Why I enjoy games and puzzles

We ask about the different ways people keep healthy and well, whether they have dementia or not. This issue, we hear how games and puzzles help six readers.



Belinda Ratcliffe, 70, Morecambe

I play online solitaire and 'June's Journey' – a game on Facebook with hidden objects – and do jigsaw puzzles. I also do crosswords and sudoku in

Puzzler collection magazine and daily newspapers.

My sister, who has advanced Alzheimer's, and I used to do puzzles together when she was well. I find it keeps my brain alert, and the hidden objects game is a memory challenge.

Sue Pope

I play board games with my partner at least once a week, and more rarely with friends and family. We don't have a TV and I have always enjoyed playing games. It is fun and I have become more skilful at them.

Barney Thompson, 66, County Antrim, with dementia with Lewy bodies

I play games like Assassin's Creed on the PS4. The way the game progresses, I could play it today, pick it up tomorrow and remember where I was – it triggers all the right buttons. If you do it in easy mode it guides you along. You can live life through what you're doing on screen, and you're in full control.



Jemma James, 39, Durham

I enjoy PC games, role-playing games and LARPing (live action role-playing) two or more times a week. They're fun, they exercise my

imagination, relieve stress and keep me fit.

I balance work, hobbies and recovery time carefully due to living with fibromyalgia and chronic fatigue syndrome. However, through gaming I've made lifelong friends, developed my creativity and improved my teamwork skills.

Jeffrey Sutton, Bishop Auckland, with dementia

I do cryptic crosswords in newspapers, and I play Scrabble and cribbage online. I do several hard crosswords and play Scrabble against an opponent every day.

I do it to keep my brain active and train my memory, and to stave off dementia for as long as possible. My mobility is impaired and I live alone. It keeps my mind alert and the online conversations as I play are useful for social interaction.



Bo Ruan, 32, London

I love role-playing video games where there is a deep story and I have to put myself into character to make decisions. It engages the brain and it forces you to be in the

moment and forget your other daily worries.

Since having children, I only play a couple of hours a week and mostly by myself now. I focus more on games I can play on the phone or for shorter amounts of time. Playing games that don't require the sound to be on helps to not disturb others!

Stay well

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

Things you can change? Keep your mind and body active, enjoy healthier food, don't smoke, drink less alcohol, stay in touch with people, and deal with any health problems.

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

Visit www.nhs.uk/livewell for health and wellbeing advice for everyone.

Very able champions

A Dementia Friendly Communities Champion in Belfast is improving understanding of dementia among people who, like him, have a learning disability.

Joseph Turnbull is one of an inspiring group of people with learning disabilities in Northern Ireland who are helping to give their peers a better understanding of dementia.

'Years ago, if you said somebody wasn't well, they might just put you in an institution,' says Joseph. 'Today, we can take the fear out of getting dementia. The more you talk about it, the more people understand it.'

In a recent Society initiative in Belfast, people with learning disabilities took part in adapted information sessions at day centres to become Dementia Friends. Joseph is one of 11 who went on to be trained to run sessions themselves.

'Sometimes people with a learning disability can be frightened of saying, "I have dementia." But they deserve the same respect and support as others,' he says.

Adapting sessions

Dementia Friends aims to transform the way that everyone thinks, acts and talks about dementia, and you're at greater risk of developing the condition if you have a learning disability.

In Northern Ireland, Dementia Friendly Communities Champions run information sessions for new Dementia Friends. These were adapted to make it easier for people with learning disabilities to take part. The usual sessions can be divided into two or four chunks and done over time. New resources with more straightforward language and images help to explain dementia.

The best you can

Joseph refers to his own experience of dementia during information sessions. 'It helps people to understand it more,' he says.

Both of his parents had dementia, and he had to deal with its impact on the people he'd lived with his entire life.

'There were times I felt rotten,' says Joseph, 'because there was nothing I could do for them. You see different parts of the brain closing down, but you have to get on with it and do the best you can.'

'It was lonely – but it was lonelier for them.'

As a champion, however, Joseph is creating real change for other people.

'You have to be confident in what you're talking about. I can relate to people, and they feel better because somebody is listening to them. When somebody says thank you for listening to me, it makes it all worthwhile.'

Hearts, minds and more

People with learning disabilities who became Dementia Friends at the day centre sessions have been making a difference in other ways too.

This has included making their own day centres more dementia friendly as well as involving other centres across Northern Ireland. They've also helped to review our Easy Read information for people with learning disabilities.

For Joseph, the motivation to bring dementia out into the open is clear.

'It's better to talk about it than keep it hidden in our hearts and minds,' he says.



Find out more about Dementia Friends and how to become a champion at dementiafriends.org.uk





Even more determined

A supporter in Lancashire was so inspired by last year's Trek26 that she's set to do it again in 2020.

When Kirstie Banks-Lyon signed up for Trek26 Hadrian's Wall last year, she didn't expect it to be on one of the wettest days of an unusually rainy summer. If anything, 'the best efforts of the English summer to cause havoc', as she puts it, have made her even more determined to take part again.

'It was mentally tough, but there was a sense of camaraderie.'

Kirstie still gets emotional as she talks about the reaching the finish line, with people cheering her and her fellow trekkers on through the rain.

'Seeing the finish arch – I had friends and family there supporting me – it felt like such an achievement. I'm even filling up now, thinking of it.'

'We were out of our comfort zone for 10 hours; for someone with dementia, it's not something they have any control over.'

Impact

Kirstie, in Morecambe, Lancashire, has first-hand experience of the impact of dementia.

'My husband, Simon, was diagnosed with early-onset Alzheimer's in 2018, aged 58. It was a shock. All of a sudden I thought, "What do we do? What's going to happen?"'

'I was about to retire, coming up to 50, when he was diagnosed. It was something you think happens to other people.'

Kirstie, a police officer for 30 years, began to find answers on our website and through Talking Point, our online community. That's also where she read about Trek26.

'Having run a half-marathon, I thought I'd love to do the marathon distance as a walking challenge. It gave me a focus as well.'

Pride

Trek26 events take in six spectacular routes – around the Brecon Beacons, Lake District, Stonehenge, Dartmoor and London, as well as Hadrian's Wall. You can sign up for either the 13-mile route or the full 26 miles and there's support every step of the way, online and in person.

'The Facebook group was brilliant,' says Kirstie. 'Through that, I met with other walkers the night before. We did the walk together, sharing stories and supporting each other to get around.'

'I felt such a sense of pride afterwards to complete it in under 10 hours and raise over £1,000 for such a worthwhile cause.'

Here's to a sunnier day this year!

Join hundreds of others on Trek26 – visit alzheimers.org.uk/trek26 or call **0330 333 0804** to find out more.

For your big day

Our specially designed wedding favours look amazing and help to support our vital work. The range of forget-me-not pin badges, which can also be attached to our foiled table cards, includes silver, blue, sparkling and new gold versions.

They are an extra special way to honour your loved one with dementia while giving your guests a meaningful keepsake of your special day.

See the Celebrations range at shop.alzheimers.org.uk or call 0300 124 0900 (local rate).



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

Making North Belfast dementia friendly

Organisations and activists came together to officially launch Dementia Friendly North Belfast at the end of last year, at an event attended by the Lord Mayor and local politicians.

Emily Wilson, Information Worker at Alzheimer's Society, said, 'We showed a video of Pat Smyth, who cares for his wife Angela, talking about their dementia journey, which really helped people to understand the reality of everyday life when living with dementia.'

Fiona Brown, our local Services Manager, added, 'Dementia-friendly communities are vital in helping people to live well with dementia and remain a part of their community. It was brilliant to see so many people involved and passionate about transforming North Belfast.'

As well as providing information hubs and involving local traders in supporting people affected by dementia, there are plans to deliver training in primary schools across the area.



Research on your doorstep

In December, supporters in north Wales were brought face to face with some of the vital research that they're helping to fund.

At the Dementia Research on Your Doorstep event in Bangor, a Society-funded researcher at Bangor University shared her cutting-edge work. Lovesha Sivanantharajah explained how her research is throwing light on why some parts of the brain are more vulnerable to Alzheimer's than others.

'We had an impressive turnout – around 50 people, despite terrible weather!' said Lovesha. 'There were fundraisers, volunteers and people with dementia, as well as researchers and students.'

Supporters were thanked for their hard work, and Sam Pugh spoke about completing seven challenges before her 70th birthday to raise money and awareness.

Helen Marchant, Community Fundraiser at the Society, said, 'We couldn't do what we do without our fantastic fundraisers and volunteers, and this event gave them an insight into exciting work happening right on their doorstep.'



Boxing Day bravery

Two young friends braved the chill of the midwinter North Sea to help fight dementia on Boxing Day, raising £1,100 in the process.

Maisie Bruce and Nicole West, both aged 12, earned our admiration and thanks by taking a dip in the icy waters at South Shields. They raised funds through sponsorships and a bucket collection on the day, with the funds split between Alzheimer's Society and a local dementia charity, Ocean Choices.

Dan Nelson, our local Community Fundraiser, said, 'These very kind and caring young girls wanted to make a difference, following personal experiences of dementia within their family. They loved the dip and are delighted to know that their funds will be used to transform the lives of people living with dementia.'



Will you quit for a bit?

Sarah Maling, in our Mass Participation Events team, cut out sugar and alcohol for a month last year, and she's looking forward to Quit for a Bit this March.



Quit for a Bit is one of the newest ways that you can raise money for Alzheimer's Society, and you can join us by taking up the challenge this March.

We already have amazing events like Cupcake Day and Memory Walk that involve thousands of people and bring in millions of pounds each year. However, my team is always looking for new ideas to inspire as many people as possible to unite against dementia. We test every idea carefully to make sure it works.

Quit for a Bit asks people to raise sponsorship money by giving up either sugar, alcohol or both for a month, and it really struck a chord when we tested it last year.

As a bit of a sugar addict, I put my money where my mouth is by taking on the challenge to quit alcohol and sugar. I must admit, the first week was a struggle! Yet I was amazed by the generosity of friends and family, which helped me make it through the month and to raise more money than I had expected.

Quit for a Bit will be happening again in March – why not take up the challenge yourself?

Visit alzheimers.org.uk/quit or call 0330 333 0804 to find out more and join in.



Get your regular copy by completing the form on the inside-back cover, visiting alzheimers.org.uk/subscribe or calling 0330 333 0804

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Dementia together
magazine today**

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.



Dispelling myths

After helping to support her late father, Karenza Frear knows how devastating dementia with Lewy bodies can be. **Gareth Bracken** meets a daughter who wants others to understand.

I want to dispel a few myths about dementia,' says Karenza Frear, whose father Barry had a less common form of the condition.

Barry, a former university lecturer, had dementia with Lewy bodies. This can cause problems that many people don't associate with dementia, such as with movement and hallucinations.

'Dementia isn't just about people forgetting things here and there,' says Karenza, who lives near Taunton in Somerset. 'The reality has been quite traumatic.'

Simple things

Barry was a builder by trade, but later got a degree and became a further and higher education teacher and lecturer in politics, history and philosophy.

'Dad was quite a quiet, contemplative person who liked the simple things,' says Karenza, a senior lawyer for a registered social landlord. 'He enjoyed chess but cycling was his favourite activity. It was the one constant in his life.'

Karenza, the oldest of three siblings, says that, although there had been earlier difficulties, a visit to New Zealand five years ago exacerbated these and made clear that something was wrong with Barry's health.

'He'd been quite anxious in the build-up but put it down to not having flown for years,' says Karenza. 'On the way back, he had hallucinations and a major breakdown. He was incredibly disorientated, he didn't know where he was.'

Barry had experienced night terrors and problems with numbers and puzzles before the trip, but these hadn't been connected with anything like dementia.

'He lost confidence. It took approximately six months before he felt confident going out again, though he never fully recovered,' says Karenza.

Worried and scared

A doctor put the incident down to severe jet lag, and nothing led the family to believe that Barry might have dementia.

'We could always explain the changes in Dad in other ways,' says Karenza. 'When he was withdrawn, we thought he might have depression. When he struggled to take on board new things, I put it down to him not paying attention. Other times we said it was his confidence.'

Karenza believes that her dad made sure the family only saw him on his better days.

'I think he knew something was wrong but didn't let on,' she says. 'Thinking back, he was probably quite worried and scared.'

Barry's health gradually deteriorated. He had one fall, and he sometimes passed out if he got up too quickly after a daytime nap.

Hospital hallucinations

Around two years ago, Barry was taken to hospital after passing out. Aged 70, he remained there for a month, and he was diagnosed with

dementia with Lewy bodies. He experienced very bad delirium and hallucinations in hospital.

'It was horrendous, he'd suddenly become hysterical,' says Karenza. 'It was horrible to see him upset. Once he moved onto a side ward, his delirium eased and he became more lucid.'

Dementia with Lewy bodies

Around 10–15% of people with dementia are thought to have dementia with Lewy bodies. Often mistaken for Alzheimer's disease, it also shares symptoms with Parkinson's disease.

People who have dementia with Lewy bodies can have problems with attention and alertness that vary over time, and difficulties judging distances. They may see or hear things that aren't there, have persistent false beliefs or experience disturbed sleep. Difficulties with movement, which increase the risk of falling, affect many people with the condition.

As with other types of dementia, symptoms increase and get worse over time. As it progresses, day-to-day challenges become more similar to other types of dementia.



Quick read

Karenza Frear wants healthcare professionals and the public to understand more about dementia with Lewy bodies.

Her late father Barry, diagnosed with this less common form of dementia, experienced very bad hallucinations and delirium.

Karenza says that film and television portrayals of dementia don't always represent what her father went through.

Karenza advises people in a similar situation to use the information and resources available so that they know what to expect.

Barry moved into a specialist dementia care home straight from hospital, where his partner and daughters visited him regularly. He was more settled in the care home, and Karenza recalls him interacting with other residents.

‘The home was well-equipped to deal with his needs, though I don’t think he ever knew he was in a care home, she says. ‘I think he thought it was a hotel or something like that.’

As she looked to best support her dad, Karenza found useful information on Alzheimer’s Society’s website.

‘It had easy-to-use guidance on managing symptoms, and how to navigate through the whole process from hospital discharge to what care and benefits were available,’ she says.

Never easy

Karenza successfully pushed for Barry to have an initial assessment for NHS continuing healthcare – a care package funded by the NHS. But they were then told he wasn’t entitled to a full assessment because he had dementia.

However, Karenza challenged this and secured the full assessment nearly two years later. Eventually Barry’s entitlement to

NHS continuing healthcare was recognised, but that was nearing the end of his life.

‘None of it was easy. You’re constantly having to chase things up at an already difficult time,’ says Karenza.

Barry died in October, aged 72. ‘We were with him 24/7 when we knew it was end of life care,’ says Karenza. ‘That last week he was calm, no panic or hallucinations. In some respects, it was a bit of a relief.’

Very unpredictable

Karenza is keen for everyone to understand more about dementia with Lewy bodies, including health professionals.

‘I think people are getting more aware of dementia generally, especially Alzheimer’s, but I also think that the portrayal of dementia in film and television is slightly romantic – older people losing their memory but not really caring,’ she says.

‘It wasn’t Dad losing his memory, it was his inability to process things or learn new things.

‘The recent Elizabeth is Missing adaptation was very good and portrayed some of the aggression and the nasty side, but it still didn’t go as far.

‘Sometimes Dad would get frustrated, shout, swear a lot and smash things up. It was all the disease. But then he was also very polite and caring. His motor and mental functions could flip in a millisecond, it was very unpredictable.’

Most important

Karenza hasn’t always been able to identify with the outlooks of other people affected by dementia.

‘I’ve seen people saying that dementia isn’t the end of the world, but in my experience it was,’ she says.

‘It looked like Dad was going from one tormented nightmare to another. He was bedridden for the last six months of his life and, whenever I saw him, he was either asleep or screaming.’

Having seen the impact that dementia with Lewy bodies can have, Karenza advises people in a similar situation to seek out information, advice and suitable support.

‘The right resources can help you know what to expect,’ she says. ‘And if a person is receiving care, get them a care home that understands the needs of different types of dementia. For me, these were most important.’

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

Find support near you by using our dementia directory – see alzheimers.org.uk/dementiadirectory

For our What is dementia with Lewy bodies (DLB)? (403) factsheet, go to alzheimers.org.uk/publications or call **0300 303 5933** (local rate).

Karenza with her sister Jannah and dog Billy.



More than medicine

Social prescribing is helping people in Rotherham to stay healthy and well by connecting them to local activities. **Gareth Bracken** reports on how people with dementia are benefiting.

Quick read

A pioneering service is helping people with health conditions in Rotherham to stay well by 'prescribing' them activities.

Alzheimer's Society is making sure that people with dementia are included by providing a specialist aspect to the service.

Margaret, who doesn't otherwise see many people, says that the lunch club she was introduced to gives her something to look forward to.

The Society is working with NHS England to ensure that social prescribing services are dementia friendly.

A scheme in Rotherham is supporting people's health and wellbeing by 'prescribing' them activities in their community, and Alzheimer's Society is making sure that people with dementia can benefit from it.

Rotherham Social Prescribing Service, part of Voluntary Action Rotherham, is helping people who have long-term health conditions and mental health issues.

'We're trying to reduce hospital visits and the number of people having to go into residential care,' says Barry Knowles, who manages the service.

Referrals from GPs include people who are at a higher risk of going into care. As a number of these are people with dementia, the Society was commissioned to provide a specialist dementia enabling service.

'It's about prevention through social and physical activity rather than long-term support,' says Barry. 'If people have the knowledge and confidence to continue attending the group or activity themselves, that's a really positive outcome.'

Out and about

Kirsty Veitch-Sorsby, Dementia Support Worker at the Society, oversees the specialist dementia service.

After an initial phone call, Kirsty visits the person with dementia to better understand their personality and interests. She can then suggest local groups or activities that could suit them, having already researched and visited groups to ensure they're appropriate and accessible. She also helps arrange transport, or even takes the person herself.

'We're getting them out and about to different places in the community,' she says. 'A lot of people don't have the confidence to go out, but if you sort out the transport it can alleviate a lot of the problems. It opens up people's lives.'

Kirsty has introduced people to lunch clubs, activity groups, memory cafés, Singing for the Brain and the Women's Institute. One 78-year old woman started going to the gym through the service.



'Sometimes at groups, people will mostly talk to a person's carer, but this service doesn't focus on the carer, which can be valuable,' says Kirsty.

The groups aren't always specifically designed for people with dementia, so Kirsty has been running Dementia Friends sessions to improve people's understanding of the condition and how they can support someone affected by it.

'It needs to be sustainable,' she says. 'If it's a weekly club and people are getting the hang of it, at that point my work is pretty much done.'

'People are still going and still integrating, and they say it's made a difference to them, so that's a success.'

Best ever

Kirsty has introduced three people with dementia to a Salvation Army lunch club and they continue to attend every Wednesday afternoon, socialising and supporting each other along the way.

Ray Bletcher, 78, whose wife died six years ago, enjoys going to the club.

'I'm quite happy going there, it saves me cooking and gets me out!' he says. 'The meals are very good and I get on with the cooks. They're good and sociable.'

Ray is also full of praise for Kirsty.

'She runs me about and brings me back home. She's great – 20 out of 20!'

Joining Ray at the club is Margaret, who speaks extremely highly of it.

'It's fantastic, the best one I've ever been to,' she says. 'The lady behind the counter deserves a medal!'

The opportunity for social interaction has made a real difference to Margaret.

'I don't see any neighbours or anyone much, so this breaks things up in a long, lonely day,' she says. 'It gets me out of bed and dressed, and is something to look forward to.'

'It brings people together. I've spoken to a new couple this week who I wouldn't have spoken to otherwise.'

Doreen Guest says that Kirsty has given her 'really good' support, including arranging alternative transport.

'I like to go out, but can't on my own unless I get help,' she says. 'The bus is harder as I can't lift my legs and am frightened of the lift, but they are sending a bus with a ramp.'

At the lunch club, Doreen appreciates the time she spends with others.

'I like talking to people and they are all really friendly,' she says.

'I don't like being on my own. I've got my cat Toby but I miss my friends where I used to live. This gets you out of the house.'

More personal

Social prescribing is a key part of NHS plans to make the care received by people with dementia in England more personal to them.

'This recognises that health is more than medicine and marks a shift towards community connections and social activity,' says Ian McCreath, Personalisation Lead at Alzheimer's Society.

'We're working with NHS England to understand the impact that social prescribing can have for people following a diagnosis. We want to ensure that people working within social prescribing understand dementia and make their services inclusive and dementia friendly.'



To find out if social prescribing is available in your area, speak to your GP.

Call 0300 222 5706 (local rate) or email volunteers@alzheimers.org.uk to find out more about volunteering for Alzheimer's Society.

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

Reading interest

A Montessori approach is helping people with dementia to enjoy a feeling of purpose. **Gareth Bracken** visits a book club that's raising self-esteem.

Quick read

The Montessori philosophy, usually associated with early years education, is being applied to supporting people with dementia.

The founders of Dementia the Montessori Way say that their methods can improve a person's self-esteem and sense of belonging.

The approach includes holding book clubs in hospitals and care homes, where groups read and discuss specially written books.

Joan, at Ashbourne Lodge in Derbyshire, says the books and the clubs are 'marvellous' and 'very entertaining'.

The Montessori approach is most closely associated with early years education, but its methods are being used to help support people with dementia. Dementia the Montessori Way was set up by Lynne Phair and Sally Dando, two experienced healthcare professionals.

'Montessori enables people with dementia to be as independent as possible, have a meaningful place in their community, make a meaningful contribution to that community, have high self-esteem and a feeling that they belong,' says Lynne, an Independent Consultant Nurse.

Specialist book clubs, in hospitals or any care setting, have been a key element of this approach. Facilitated by staff or family members, the clubs are a place for people with dementia to enjoy conversation and company. Some of them achieve specific goals, such as reading a certain amount, while others simply benefit from the stimulation.

The books they read are especially written by Lynne and Sally for people with dementia. Professionally published, the books don't contain distracting pictures. How the writing looks, including its size and how it's laid out on the page, has been tested with groups and individuals to make sure that people with dementia can enjoy the books.

Conversation topic

It's early December and the book club at Ashbourne Lodge care home in Derbyshire is reading 'Deck the halls!'. Guided by Maddi, the home's Activity Co-ordinator, they take it in turns to read a page each, with support where required. The Christmas-themed book prompts conversation about mulled wine, stockings and Santa.

'There were a lot of things in there I didn't know about at all,' says Iris. 'These books are nearly always full of things I'd never heard of.'

Next on the reading list is 'Anyone for tea?', about the history and culture of tea drinking. The group has previously read books about the Queen, the nearby Derwent Valley and school sports.

'It said that physical education is sometimes a lesson that kids dread. I might have been one of the ones who dreaded it the most – hockey on a rainy day!' says Iris.

Courtesy and grace

Supporting Maddi with today's club is Stacy Sandham, Lead Activity



Photographs: Mark Harvey

Visit www.dementiathemontessoriway.co.uk for more about Dementia the Montessori Way.

Co-ordinator at Ashbourne Lodge.

'We make the group relaxed, like people were reading at home, but also sociable,' she says.

'It's lovely to hear the books read out, especially by people who don't say much. Even if a person struggles to read, they are still able to join in. It's also lovely to involve residents who aren't able to leave their beds – we go to them two or three times a week.

'The books are really good and prompt a lot of reminiscence. They provoke different stories for different reasons.'

The book clubs have been a success in hospital too, explains Lynne's colleague Sally, an Occupational Therapist.

'I have a team of occupational therapy assistants, trained as facilitators, who go onto a bay and invite people to join the book club,' she says.

'It's a great activity to get people out of bed and talking to each other. We've had a number of

lightbulb moments – people who are not happy in hospital but join in an activity and blossom.'

The books are designed to be straightforward but not patronising, and to raise a reader's self-esteem by helping them to succeed. However, as Lynne points out, the Montessori influence isn't found within the books themselves, but rather in how they are used.

'It's about invitation, courtesy and grace,' she says. 'Value a person, give them a role and think about their strengths. That gives them a sense of interest, purpose and enjoyment.'

Very entertaining

Pat enjoys the books as she can relate to the subjects, while Tom, a group member who doesn't have dementia, finds that they bring back memories.

Joyce finds the books quite easy to read, while Joan says that the larger print makes things more

manageable. Joan, who's building her confidence reading after some time away from the group, describes the books and the club as 'marvellous' and 'very entertaining'.

The group is small, which Pat finds easier to cope with, while its humour and camaraderie also appeal.

'We're friends – the group are like a cloak around,' she says. 'We laugh about things, I love doing the group.'

Joyce, who particularly liked the book about the Queen, enjoys getting praise for her reading. 'I'm a lover of that,' she says.

Joyce is happy to involve herself in any activity she can, while Iris is very much the opposite.

'Usually I don't like doing things, but I've enjoyed this,' she says.



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

Find dementia services near you using our dementia directory at alzheimers.org.uk/dementiadirctory

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

Letter of the month

Repetition, repetition, repetition

Thinking about why dementia is a difficult condition for carers, I found the repetition of certain sentences hard to cope with initially.

Yesterday, Mum came over and repeated seven times in two hours, 'I think it's good that Jim [her son-in-law] plays tennis every day from 9–11am.'

How should we deal with this? It's something you would not encounter with anyone else in a social situation. I like thinking about why this particular fact is so important to Mum that she wants to tell us over and over.

She is very fond of her two sons-in-law, so anything to do with them is interesting to her. She used to play tennis every week, so again there is a link to past times when she could play tennis, which she really enjoyed. Then I think well, she does not remember she has told us already, so the thought keeps coming back to her, and to her it is the first time.

Trying to stay positive in the face of this onslaught of repeated phrases is not easy, but finding a reply that we can repeat back to her keeps her happy and prevents our frustration and boredom from increasing. So we started to say, 'Yes, that's good isn't it? That he plays tennis at 65.'

Going out for picnics in the summer (pictured) really helps as well, as there are other things and people to look at and talk about, so we enjoy her visits more. These are just two ways we have found to live better with Mum's dementia and help her live a happier life too.

Ruth and Robert Cole, Hampshire

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



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
 Letters for the April/May issue
 to arrive by 6 March. Views
 expressed are not necessarily
 those of Alzheimer's Society.
 Letters may be edited.

Seen elsewhere...



Dementia Friends Champion Ripaljeet Kaur at Touchstone Support celebrated a successful session with local service Live Well Leeds by sharing a picture on Twitter:

14 more #DementiaFriends created @Touchstone_Spt. Thank you @LiveWellLeeds team for being awesome during my session. Shout out to Steve for joining our internal #DementiaChampions group.



When we shared a message of support for carers on Facebook at the start of the year, it prompted Beverley Wolfe to reply:

Alzheimer's Society's website and telephone line were so helpful when my auntie was first diagnosed and continued to be a support for my mum and cousin throughout her illness. Lots of information on the website. My cousin and I are going to take part in Memory Walk this year in memory of my lovely aunt. Keep up the excellent work.



Talking Point, our online community, ran a 'virtual Christmas thread' for members to share how they were doing over the festive period, which many people were thankful for, including Marnie63:

I will be forever grateful to the people on Talking Point whose words were such a source of comfort and support when I was going through my dark times with Mum's illness. And I will always be in debt to Alzheimer's Society, who provide such a brilliant and well-run resource for those affected by this cruel and challenging condition. Thank you everyone.

Free TV licence with Pension credit

Over 75s will no longer get free TV licences from June, but you can still get one if you receive Pension credit. Many people who are eligible for Pension credit don't claim it, but if your claim is successful it can help in lots of other areas too.

Pension credit is a means-tested benefit for people over the state pension age. If you have it, you may also qualify for help with housing costs or other support.

The BBC is asking people affected by dementia, including through our Focus on Dementia network, to help implement changes to TV licensing in the best way.

Find out more about Pension credit at www.gov.uk/pensioncredit or call 0800 99 1234.

Right to a personal health budget

More people in England now have the right to a personal health budget. As well as people receiving NHS continuing healthcare, you now also have a right to a personal health budget if you're eligible for an NHS wheelchair, or if you're entitled to aftercare after being detained under section 3 of the Mental Health Act.

Personal health budgets can give people greater choice and control over the services and care that they receive.

Find out more about personal health budgets at www.england.nhs.uk/personalhealthbudgets



‘My aunt has dementia and may need to move into a care home soon. Will she need to sell her home to pay for her care?’

Selling a home to pay for care

Your aunt won't necessarily have to sell her home to pay for her care – it depends on her circumstances.

Her local authority will assess her finances to see how much of her care fees she must pay herself. There are situations where her property wouldn't be included in this financial assessment. Even if it is, there might be alternatives to selling her home.

Care at home

While your aunt has a care package at home that meets her needs, this home will not be included in her local authority's financial assessment.

Many people with dementia live well at home for many years, adjusting their care package as their needs change.

‘Qualifying’ people

If your aunt needs to move into residential care, her local authority must ignore her home in its financial assessment when particular people also live there.

This is called a ‘mandatory property disregard’ and it applies while a ‘qualifying person’ lives in your aunt's home. That could be a partner or spouse, or an estranged or divorced partner if they're a lone parent. It also includes certain relatives who are disabled or aged 60-plus. If your aunt has children aged under 18 who live there, it applies to them too.

More leeway

If there isn't a compulsory reason for the local authority to ignore your aunt's home in its financial assessment, it may still use its discretion to not include it.

For example, it might do this if someone has given up their own home to move in with your aunt and care for her. This isn't guaranteed – it's the local authority's choice over whether it provides this leeway.

Rent or defer

If your aunt's home is included in her local authority's financial assessment, she may need to sell it to pay for her care. However, there might be ways to avoid or delay this.

Some people can rent out their property and use the rental income to cover care fees. This wouldn't suit everybody, but it could work for some.

Others make an agreement with the local authority to ‘defer’ or delay paying for care. Costs usually need to be paid back within certain timeframes, with fees and interest added. For some people, this means they don't have to sell the home, at first or at all.



For our Paying for care and support in England (532), Paying for care and support in Wales (W532) and Paying for care and support in Northern Ireland (NI532) factsheets, see alzheimers.org.uk/publications or call **0300 303 5933**.



You can complain to the local authority if you disagree with it including a person's home in a financial assessment for care costs.

For legal advice, Solicitors for the Elderly could help find a solicitor near you with relevant experience – see www.sfe.legal or call **0844 567 6173**.



Jean Eastwood, Nottingham, aged 71 with Alzheimer's

What's changed most since your diagnosis?

Friendships, mainly. I've lost a lot of old friends but gained a lot of new friends. When I was first diagnosed it was quite a dark time, and they understand me more.

What would you take to your desert island?

The Bible, it's very important to me. I go to three churches – one for the music and atmosphere, another I've been going to for 29 years, and a local church too.

How has Alzheimer's Society helped you?

When I first got my diagnosis, the Society was one of the first places I went to. I'm a great believer in getting whatever advice you can.

Alzheimer's Society has offered me support and they've also given me a lot of opportunities, like hosting a session at last year's annual conference. I'm also in our local Focus on Dementia Network group, I volunteer and go to Singing for the Brain, and I'm in the Dementia

Choir that was formed with Vicky McClure for the BBC One programme. When you live on your own, you need to get out and do things.

What song or tune sums up your life so far?

The wonder of you, by Elvis Presley. I could never sing it without crying. The opening lyrics remind me of my late husband – we were together 40 years and he was always there for me. I supported him and he supported me.

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

My husband and I used to go to Guernsey when my son worked there. One time, we surprised him by taking our grandson with us. I phoned him after we arrived and he heard my grandson shout out. He said, 'Is that Richard?!' I stood and cried with happiness on a Guernsey beach.

What is your most treasured possession?

My memories. I have lots of memories of wonderful people.

If you have dementia and would like to answer our questions for a future column, email magazine@alzheimers.org.uk or write to the address on p3.



Who will you walk for?

Shine a light on dementia at **GLOW**, Alzheimer's Society's brand new night walk.

Sign up today:

memorywalk.org.uk/glow
0300 330 5452



We took a new range of specially designed clothes for men to a group of people with dementia in Peterborough.

Menswear range

Peterborough's Healthy Memories group for men meets weekly at the local Dementia Resource Centre. It's a friendly place for men with dementia to enjoy different activities, and we asked for their feedback on a range of clothes for men, specially designed to be easy to put on and take off.

The Able Label was founded by Katie Ellis after she struggled to find stylish clothes for her grandmother, who had Parkinson's disease dementia. Whenever we showed people the company's womenswear, they asked about similar clothing for men. The Able Label responded by developing a new range.

Shirts and ties

We showed the group two shirts, both with buttons going down the front, though these are purely decorative. Behind each button is a strong velcro pad, and it's these that you use when dressing.

Barry liked the idea of hidden velcro fasteners. 'I think it's handy,' he said, 'I like that.'

Frank agreed, 'Buttons are no end of trouble – they never make buttonholes big enough.'

Alison, a volunteer at the group, wondered if the back of each velcro pad might scratch your skin, though Frank, feeling them, said, 'I think it would be OK.'

The more formal looking white shirt, called 'Hugo', also comes in blue. The other, 'Miles', had a floral

pattern, and is also available in stripes or checks.

Apart from them being helpful, Jim said the shirts are 'very fashionable as well'.

Although Frank wasn't a fan of the floral version, the other 'Miles' shirts were more his style. 'The pattern's too fancy for me,' he said. 'I prefer stripe or check.'

'I like a button-down collar,' added Jim, 'like the one on the striped shirt.'

'Miles' is 100% cotton, while 'Hugo' is a cotton/polyester mix and needs no ironing.

The group approved of the navy 'Calvin' clip-on tie, which also comes in black and burgundy. Frank suggested adding a bowtie because he enjoys wearing one and, 'I like everything as easy as possible.'

Trousers and belts

When we looked at a pair of stone-colour 'Spencer' trousers, which have a velcro fly, group members agreed that trousers cause particular problems.

'Trousers are the hardest thing to do,' said Jim. 'You've got to stand up to put them on, pull one leg up and then the other. With these, you wouldn't have to fiddle with buttons or anything like that.'

'All my trousers have zips,' said Frank, 'which all wear out and are expensive to replace.'

Barry asked if the 'Spencer' trousers are available in other colours because, 'I like dark colours.' Fortunately, there's

also a midnight blue version.

The trousers only come with a 78.5cm (31") inside leg, which Barry said would be too long for many. The Able Label can shorten the leg to your measurements before despatch, costing £12.

Barry said, 'It would be good if it had a stretchy waistband – that helps if you've got a belly, especially after a meal!'

Although the velcro used is very strong and designed to last, Jim worried about trousers bursting open. Just one button or hook at the top would help to make sure.'

Everyone was pleased that the brown Able leather velcro belt comes in four different sizes, as the one we had was too small when they tried it on.

Once again, people wanted to feel secure about the belt's velcro fastening. After pulling as hard as he could on it, Frank said, 'It feels pretty strong.'

Nightwear and zipper help

We had brought three nightwear options to the group. The 'David' brushed cotton pyjamas includes a T-shirt and the 'Matthew' pyjamas a shirt top, both with pull-on bottoms. The long 'John' nightshirt is also brushed cotton, with velcro fastenings down its front.

Barry liked the material used in 'David' and 'John', saying, 'It's nice and soft.' However, Jim said, 'Brushed cotton would be too warm for me to sleep in.'

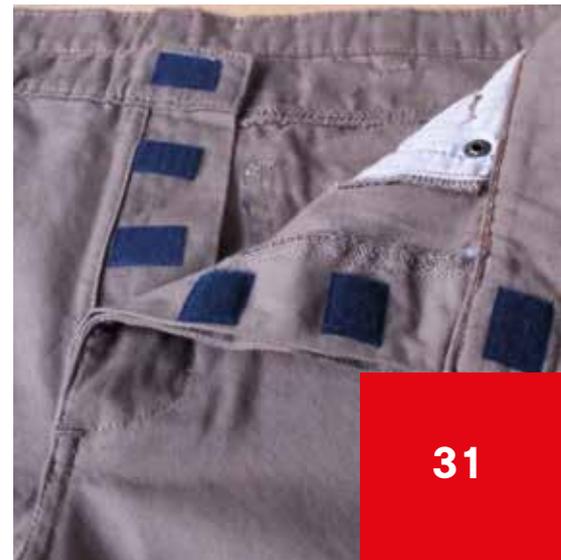
Alison noted they all had 'do not tumble dry' labels, which could cause problems rotating between them if they don't dry quickly enough.

The prices of all the menswear items (see below) were on the high side compared to what group members normally spent on clothes. However, they recognised that this reflected they were well made and specially designed.

Frank said, 'The quality is obviously there – even I can tell that!'

The group also liked the zip pulls that can be attached to zips on jackets and coats, making it easier to open and close the zip.

Without VAT, the 'Hugo' shirt is £37.50, the 'Miles' shirt £41.63, the 'Spencer' trousers £43.75, the Able belt £24.96, the 'David' pyjama set £33.29, the 'Matthew' pyjama set £41.63 and the 'John' nightshirt £33.29 (you don't have to pay VAT if it's bought to be used by a person with dementia or other condition). The 'Calvin' tie is £16 and a pack of two zip pulls is £6.



10% discount

Use our special code for a 10% discount – visit www.theablelabel.com or call 01622 744242 and use the code ALZ5 at checkout.

A range of other helpful products and gifts are also available from our online shop, see shop.alzheimers.org.uk or call 0300 124 0900 (local rate).



Win a pyjama set

See p39 for a chance to win



'I'm partially sighted and I care for my stepfather, who has dementia with Lewy bodies. The dementia information I've got from his doctor has felt really patchy.'

Whether you're diagnosed with dementia or supporting someone who is, it's vital to get information and advice that is reliable and useful.

Alzheimer's Society helps people in many different ways (see opposite), including through our publications and online information.

We do everything we can to make sure our information is accurate and up to date, and people affected by dementia help us to make it clear and relevant.

Of course, we want anyone to be able to make use of our information, including partially sighted people – call our support line on **0333 150 3456** or visit **alzheimers.org.uk** to see how we can help you.

Devices and tools

Our website is designed so that people with different needs can use it easily.

You can change your device's settings to make text larger, magnify the screen, change colours and fonts, make a mouse pointer easier to see, or use a screenreader to read what's on the screen out to you.

For details about how to do these things, see My Computer My Way at **mcmw.abilitynet.org.uk**

Magnifiers and other tools can make it easier to read printed publications. For ideas and products from RNIB, visit **shop.rnib.org.uk** or call **0303 123 9999**.

Factsheets

Many of our factsheets have audio versions that you can listen to online or on CD. There are 15 audio factsheets, and they include What is dementia with Lewy bodies? (403), Understanding and supporting a person with dementia (524) and Carers: Looking after yourself (523).

Visit **alzheimers.org.uk/audioandvideo** for a link to a playlist of these audio factsheets. To order any of them on CD, email **orders@alzheimers.org.uk** or call **0300 303 5933**.

All 70 of our English language factsheets are available online as large print PDFs, which can be read on screen or printed off.

Find the factsheet you want at **alzheimers.org.uk/publications** and click 'PDF printable version'.

The dementia guide

The dementia guide is for anyone

who has been diagnosed with dementia recently, and it includes a lot of useful information for carers.

You can listen to it online or order a CD – see **alzheimers.org.uk/dementiaguide** for links. You can also order the CD by calling **0300 303 5933**.

Magazine

Dementia together magazine shares real-life stories and ideas that help people to live well and to unite against dementia.

Hear people with dementia speak for themselves in the audio version of our main interview from each issue. Play interviews online or download them to listen later – see **alzheimers.org.uk/podcast**

You can also receive an audio version of each full magazine on CD – email **enquiries@alzheimers.org.uk** or call **0330 333 0804**.

16:56

Dementia together podcast

We share some stories from our magazine as podcasts for people to listen to, on their own or with others.

Dementia together, the magazine of Alzheimer's Society, is produced six times a year for everyone in the dementia movement and anyone affected by the condition.

You can find all of our magazine podcasts below, beginning with the most recent. The full list is also available on [SoundCloud](#) and transcripts are available on request from audiovisual@alzheimers.org.uk

- Alzheimer's Society - The best of L... 1:18
- Alzheimer's Society - Anything I can do - Deme... 1:58
- Alzheimer's Society - How I am now - Dementi... 2:18
- Alzheimer's Society - Bang the drum - Dementia... 2:38
- Alzheimer's Society - Each day as it comes - D... 3:28



To find out more about our publications, see **alzheimers.org.uk/publications** or call **0300 303 5933**.



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)

Registered charity No. 296645

19594SD

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

Person living with dementia





Readers share their views about an intriguing verse novel portraying a friendship between a young runaway and a woman with dementia.

Toffee

Sarah Crossan is Ireland's current Laureate na nÓg, or children's laureate, and she wrote *Toffee* with young adult readers in mind. Although it certainly appeals to teenagers – and the publisher provides teaching resources for Key Stages 3 and 4 to support this – it's also been well received by a much broader audience.

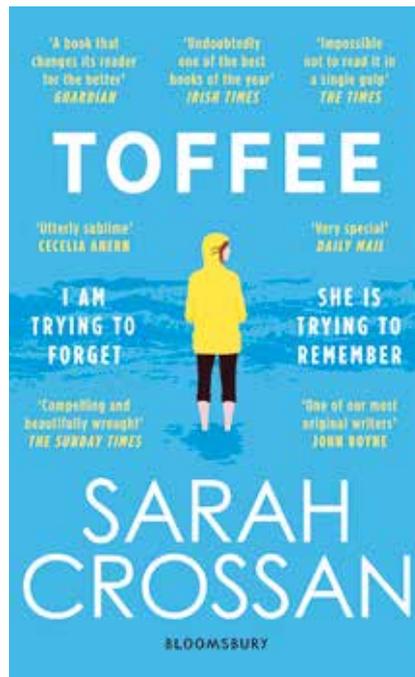
Neroli Harris, in our Dementia Knowledge Centre, was surprised and enchanted by the book.

'Toffee is written in accessible verse,' she says. 'This is not a format I have encountered before and my immediate thought was that it was going to be a book of poetry tackling some very tough concepts – violence, dementia, deceit and denial – and so not an easy read in any form.'

'However, as well as being novel, this is a novel. We have Allison, a runaway abused child with guilt and deceit issues, an abusive father, a fleeing stepmother, and Marla, a woman living with dementia, with busy grown-up children and even more busy carers.'

'Halfway through, I remembered I was supposed to be reviewing the book and that, instead of just losing myself in the story, I should start noting why it was so impactful!

'It is no wonder that Sarah Crossan opens her book with



Carl W Buehner's quote, "They may forget what you said, but they will never forget how you made them feel."

Gloria Potter in London, whose husband has vascular dementia, agrees.

'What a beautiful, moving, sad but enjoyable book to read, hard to put down once I started,' says Gloria.

'At first, I wasn't too sure of the read as written in verse. But it was so easy and engrossing. Two people, one old and one young, with no one else to talk to or understand them. Both need each other and accepting the way they were, no questions asked, and

they have more support from each other than from their own families.'

Jacquie Hunt, another reader in London, says, 'I found the story so moving. Lots of things in the book reminded me of my late mum.'

'Toffee is a very interesting and factual book,' adds Rasila Mehta, also in London. 'It's an eye-opener – more needs to be done for vulnerable people of all ages.'

Powerful narrative

Neroli was impressed by the style of writing and how it is presented.

'The writing is remarkable,' she says. 'The verse portrays a very powerful narrative. Some pages only have one or two lines, but they depict so much.'

'The chapter "Crosswords" is a wonderful combination of wordplay, page layout and revelation. In previous verses, we have learnt about violence and abusive events between Allison and her father. Here, we see Allison benignly come to the realisation that some relationships are a puzzle and will never be solved.'

'In later verses. Allison begins to understand that, when Marla becomes angry, it will not lead to violence, and that it is just pure frustration.'

'Toffee is peppered with insightful analogies. In the verse "Bad weather", both young and

old are feeling the clouds closing in, and they wait together in quiet understanding until the fog clears. This book is a great celebration of intergenerational relationships, no matter how they come about.'

Gloria says, 'I thoroughly enjoyed the read and I shall pass the book onto friends,' but Jacquie has beaten her to it.

'I have now given it to my friend whose mum has recently been diagnosed with vascular dementia,' says Jacquie.

Toffee by Sarah Crossan
(Bloomsbury 2020),
416 pages, £7.99,
ISBN: 9781408868133.

Film and TV adaptations

A number of books about dementia have been adapted for cinema and television. You can watch some using streaming services, whether through your TV or another device. DVDs are often also available from public libraries.



Elizabeth is missing

Emma Healey's debut novel quickly became a bestseller. It tells how Maud, a woman with dementia, is convinced that something terrible has happened to her best friend, prompting memories of her sister's disappearance many years before. The BBC's screen adaption, broadcast before Christmas, stars Glenda Jackson.

Available on BBC iPlayer until early June.

Still Alice

Julianne Moore met many people with dementia when preparing for her role in this 2014 Hollywood adaption of Lisa Genova's bestselling book, in which a linguistics professor discovers she has young-onset familial Alzheimer's.

Available to watch on Prime Video, BFI Player and on DVD.

Wrinkles

Paco Roca's graphic novel depicts the friendships and adventures of a man with Alzheimer's when he moves into a care home. Made into a full-length animation in 2011, Martin Sheen voices the main part in the English version (originally in Spanish).

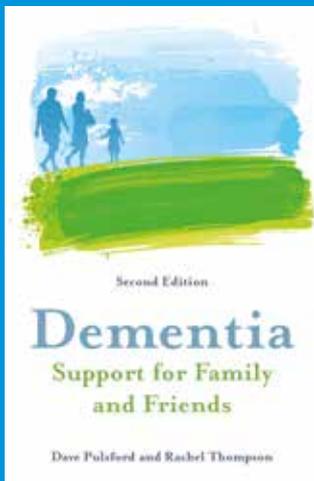
Available on DVD.

Iris

The 2001 film about novelist Iris Murdoch, who had Alzheimer's, was based on her husband John Bayley's memoir, *Elegy for Iris*. It portrays their later years alongside their youth, with Iris played by Judi Dench and Kate Winslet.

Available on DVD.

Your turn



For the next issue, we invite you to read *Dementia: Support for family and friends (second edition)* by Dave Pulsford and Rachel Thompson (JKP 2019), 304 pages, £9.99, ISBN: 9781785924378.

Let us know what you think about this updated guide for anyone who has a friend or relative with dementia. Email magazine@alzheimers.org.uk or write to the address on p2 by 9 March so we can share it in our next issue.

Book giveaway

We have five copies of the updated *Dementia: Support for family and friends* to give away – email magazine@alzheimers.org.uk or write to the address on p2 by 17 February quoting 'Support' for a chance to win one (see p39 for terms and conditions).



Members of our online community, Talking Point, share experiences of either a person with dementia or their carer falling ill.

Coping with illness

'My mum has not seen a GP for 30 years and refused to do so. Yesterday she became quite ill. I called my doctor, who is aware that Mum is living with me but refuses to see a doctor and get a diagnosis of dementia. I called 999, as advised by my doctor after they refused to come out. Mum accepted them being here, despite my anxiety. I understand I must do what she needs.' **Maisie 1**

'When my partner has been ill and not eating, soups and Complan or similar drinks were recommended.'
nae sporran

'My other half is in a much longer period of respite care this time as I have been ill, so I have been visiting, but only two or three times a week.'
canary

'Over the last three years since my dad's partner left him, I have been left to organise his care. He is now in a nursing home, diagnosed with mixed dementia two years ago. He also has advanced myeloma with no more treatment options, just palliation, because of the myeloma, which is cancer of the bone marrow that causes lots of problems.

'This included a fracture of his upper arm two years ago. He did not express pain, only rubbed his arm now and again. Luckily, we were seeing his pain doctor who x-rayed his arm. It was within a hair's breadth of breaking. He had to have surgery on it, it was probably due to the dementia that he would forget he had pain.

'He has been in hospital with many infections, which he remembers none of, but I do as I lived it sitting by his bedside wondering, "Is this it?" I think maybe it is a good thing he does not remember, but it takes its toll on you.'
Maytree

'I think the only people who really understand the stresses of caring are those who have been there and when the carer is also ill, it's even worse.

'Do you get any time for yourself? If not, please try. I know it will be an effort for you, but it might be worth it in the long run.'
Grannie G

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



Next issue

What advice would you give about dealing with things that discourage a person with dementia from getting out and about, whether feelings such as anxiety or apathy, or physical difficulties?

Email magazine@alzheimers.org.uk or write to the address on p2.



Pets and other animals

Animals can be an important part of our lives, though how we maintain contact with them may need to adapt as dementia progresses.

Many people with dementia continue to keep a pet, though they may begin to need support with walks, feeding and other care. The Cinnamon Trust can help, as well as arranging temporary or long-term care for the pet – call 01736 757900 or see www.cinnamon.org.uk

The person may enjoy time with a friend's or relative's pet, with support if needed, or websites such as BorrowMyDoggy.com or ShareYourPet.co.uk can help to find nearby animals. They could like a visit to a city farm, petting zoo or petting farm. A soft and 'breathing' Precious Petzzz simulated cat or dog might also be comforting for some people (available from our online shop – see below).

Reminiscing about previous pets can be pleasurable, perhaps looking through old photos or films, or images of similar animals found online or in books.

Favourite animals may appear on TV or in films, cartoons or books. A dog fan might enjoy Lassie episodes, Beethoven films or Marmaduke comic strips, or either reading or listening to a novel like *The call of the wild*. Some video games and apps, playable on various devices, feature animal characters or 'virtual pets'. More traditional jigsaw puzzles with animal pictures can also provide hours of meaningful activity.

Visit 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).**

Managing your money

Having dementia can make aspects of dealing with money difficult. This booklet outlines some things to think about and where to start. It also contains advice on managing your money in the future.

Check out the other booklets in our Living with dementia series at alzheimers.org.uk/publications

Order your free copy now by calling **0300 303 5933** or emailing orders@alzheimers.org.uk quoting code 1501.

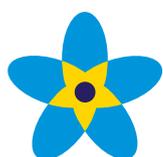




Over 3 million
people have become
Dementia Friends

Will you join them?

Visit dementiafriends.org.uk
to get involved



**Dementia
Friends**

An Alzheimer's Society initiative



**Alzheimer's
Society**

United
Against
Dementia



Menswear

The Able Label is giving a men's pyjama set, belt and non-slip socks as first, second and third prizes for three lucky winners drawn from correct entries received by 8 March.

Q: Which of these statements have we made up?

- A. The word 'pyjamas' came to English, via Hindustani, from the Persian for 'leg garment'.
- B. In recent years, UK supermarkets have faced criticism for both banning and not banning shoppers wearing pyjamas.
- C. The cat's pyjamas only go down as far as the bee's knees.

Send us your answers with your name and address – email 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.

Wedding favours

We have one set of 10 gold pin badges each for three winners drawn from correct entries received by 1 March.

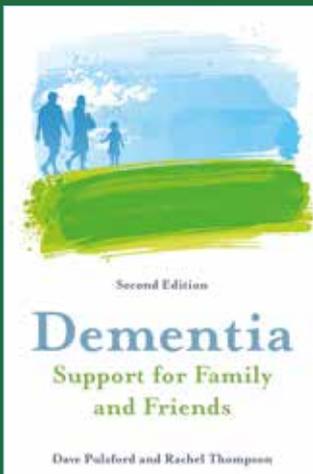


Q: Which of the following is not true?

- A. You can support us on your wedding day by using our wedding favours, asking guests to donate instead of buying a gift, or taking a collection at your reception.
- B. If you support us on your wedding day, we will accompany you on your honeymoon.
- C. You can also support us while celebrating a birthday, anniversary, retirement or any other special occasion – find out more at alzheimers.org.uk/celebrate or call 0330 333 0804.

Book giveaway

See p35 for a chance to win a copy of the second edition of *Dementia: Support for family and friends*, by Dave Pulsford and Rachel Thompson.



Precious Petzzz

C Walsh in East Sussex and M Kinson in Greater London each won a Precious Petzzz. Answer: According to the veterinary charity PDSA, of the adult UK population, 26% own a dog and 24% own a cat.

Water-free washing

Bottles of Nilaqua towel-off shampoo and body wash were won by S Sellens in East Sussex, E Bernstein in Greater London, C Davies in Powys, R Wicks in Essex, T King in South Yorkshire. Answer: 'Shampooing' is believed to have been introduced to the UK in 1814 by entrepreneur Sake Dean Mahomed and his wife Jane Daly.

Toffee book giveaway

The five readers who each won a copy of *Toffee*, by Sarah Crossan, were R Mehta and G Potter in Greater London, R Brown in Cornwall, L Close in Hampshire and R Wicks in Essex.



Get the feel-good factor

Shop our exciting range of multi-sensory products for people with dementia.

From sensory activity packs, easy-to-use music players and radios there is something for everyone.

100% of our profits go straight back into our work, supporting people affected by dementia and ultimately finding a cure.

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