

Dementia together

February/March 2019
Alzheimer's Society's magazine

Better in a crisis
Welsh ambulance

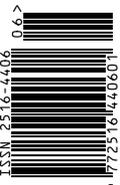
Love to move
Seated gymnastics



Time to talk
Being open

Also in this issue
Dementia Connect
Fighting for better
Exploring nature

40 years
2019



Life's rich tapestry
Active and involved

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Welcome

News

Dementia Connect 4

We have some amazing events coming up, including our new Ready Steady GLOW night walks in March (see p7), the Dementia Revolution at April's London Marathon (see inside front cover) and our annual conference in May (see p7).

As ever, this magazine is brimming with ideas for living as well as possible with dementia, as well as opportunities to make a difference for yourself and others.

Even in these uncertain times, you can be sure that we are here for you. Please make sure that your friends, family and colleagues know the magazine is here to keep everyone in touch with Alzheimer's Society and the dementia movement, and encourage them to subscribe!

Danny Ratnaik, Magazine Editor



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This is the February/March 2019 issue of Dementia together, the magazine for all Alzheimer's Society supporters and people affected by dementia.

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Contact us

magazine@alzheimers.org.uk, **020 7264 2667** or **020 7423 3676**
Magazine Editor, Alzheimer's Society,
43–44 Crutched Friars, London EC3N 2AE

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Dementia-friendly finance

Alzheimer's Society has launched a Dementia-friendly finance and insurance guide to improve how the financial sector supports customers and employees.

Developed with leading firms, the guide helps businesses to empower customers who have dementia to manage their finances for as long as possible. It also gives people working in financial services a greater understanding of the barriers these customers face.

The guide also advises firms on how to support their own staff who are affected by dementia, so they can stay in work for longer.

Roy Lewis continues to work as a manager at HSBC after being diagnosed with dementia with Lewy bodies.

He said, 'Simple steps such as providing staff with Dementia Friends sessions or ensuring they are kept up to date on the power of attorney processes and deputyship orders will protect vulnerable customers and their carers, as well as financial services employees.' **The guide can be downloaded at alzheimers.org.uk/finance**

Dementia Connect in NHS plan

The recently published NHS Long Term Plan has specifically identified our new Dementia Connect service as having a key role to play in the coming decade.

Dementia Connect combines face-to-face, telephone, print and online support and advice. We keep in touch regularly with people who use the service to ensure they get the right help as their needs change. It can also bring people with dementia together with Side by Side volunteers, who support them to continue doing the things they love. The service is currently available in East Lancashire, Birmingham and Solihull, and most of Wales, and we plan to expand it to other areas over the coming years.

The new NHS 10-year plan sets out improvements to dementia care, with a focus on more support in the community and improved hospital services.

'Dementia is the biggest challenge facing our health and care system, and the NHS Long Term Plan will help people affected by dementia get better support,' said Jeremy Hughes, our Chief Executive Officer.

'However, people with dementia can't wait for an end to the injustice in the system. We need urgent action to prioritise turning words into action. People with dementia have waited long enough for the support they need and an end to the inequity they face.'

Demand that the government fixes dementia care once and for all at alzheimers.org.uk/fixdementiacare – see p 15 for further information.

EastEnders stars to run Marathon

A group of EastEnders actors are running the Virgin Money London Marathon in support of their close friend Dame Barbara Windsor and the Dementia Revolution.

Screen icon Barbara has been living with Alzheimer's for nearly five years. Her husband Scott previously announced his entry into the marathon for the Dementia Revolution. He is now joined by an all-star line-up of Barbara's cast mates, including Adam Woodyatt, Jake Wood and Natalie Cassidy. The team – Barbara's Revolutionaries – aim to raise £100,000 for the cause.

Dementia Revolution, the London Marathon's Charity of the Year, is a partnership between the Society and Alzheimer's Research UK to raise money for the UK Dementia Research Institute.

Barbara's Revolutionaries said, 'We're taking a stand against this cruel disease in support of Barbara and everybody affected by dementia, including many of our own family and friends.'

To donate visit www.virginmoneygiving.com/Barbarasrevolutionaries



Fidget Widgets

Alzheimer's Society has been involved in developing a range of products that use 'fidgeting' movements for positive ends, helping to enhance wellbeing for people with more advanced dementia.

Fidget Widgets, wooden handheld objects that spin, slide, twist, turn or roll, are available individually or as a set of five. They were created in a joint project between Alzheimer's Society and the University of Central Lancashire that also involved people living with dementia.

Judith Bower, a Dementia Adviser and trainer at the Society, said, 'We wanted to raise awareness of how to communicate and connect with people in the later stages of dementia.

'Fidget Widgets provide opportunities for people with dementia to engage in meaningful activities that can also involve carers.'

Active Minds supplies the Fidget Widgets, which are available from our online shop. With VAT relief they cost £10.82 each or £49.96 as a set of five.

Visit shop.alzheimers.org.uk or call 0300 124 0900 (local rate).



My neighbour's wife has been diagnosed with mild cognitive impairment (MCI) – this isn't a type of dementia, but people with MCI are more likely to go on to develop dementia. As seems all too common, my neighbour got very little advice from the doctor, and at church on Sunday I could see how lost he felt. Few people could be more caring than he is, but he simply didn't know what to do.

I called round and took him a copy of our factsheet on MCI, and told him about The memory handbook and The dementia guide. Immediately he looked more relaxed, and a few days later told me how helpful the information was. Not only did he have a better idea of what he was dealing with, he also had plenty of advice about how to make life better and where to go for further support if their needs increase.

Our online services directory helps people affected by dementia to find support and activities in their area. And if you can't find what you're looking for, you can call the National Dementia Helpline on 0300 222 1122 for information, support or advice about dementia.

We are here for you – see p38 for more contacts.

Jeremy Hughes
Chief Executive Officer



Wales social care inquiry

Carers in Wales have contributed to an inquiry into the social care system by sharing their experiences of supporting a person with dementia.

The Health, Social Care and Sport Committee is looking at the impact of a law that came into force in April 2016, which was designed to strengthen social services support for carers.

Having already submitted written evidence, Alzheimer's Society staff, two carers and an advocate spoke at a session in November.

Jayne Goodrick, whose husband Chris Roberts has mixed dementia, said, 'The committee appeared surprised that some of the good practice they have had highlighted had only been unlocked by us, members of the public.

'We feel a disconnect between the ethos of the Act and the professionals' lack of understanding of it. I hope to see this wiped away by education of the professionals. This tool is only as good as those using it correctly.'

The committee will produce a report outlining the changes they wish the Welsh Government to make, based on the evidence received.

In the press

Alzheimer's from brain surgery?

December saw many dramatic headlines suggesting – wrongly – that Alzheimer's disease could be spread by blood transfusions or brain surgery.

These stories were based on new research findings that, after undergoing a now obsolete treatment, some people had a build-up of amyloid in the blood vessels of their brains. Amyloid is a protein that accumulates in the brains of people with Alzheimer's to form clumps called plaques.

The people involved had undergone brain surgery that used human growth hormone taken from the brains of dead people, some of which was contaminated with amyloid. Some of these people had a build-up of amyloid inside their brain blood vessels, but not of plaques. Although amyloid build-up in blood vessels can be seen in Alzheimer's, without the plaques it isn't Alzheimer's.

It is also important to note that this type of brain surgery hasn't been performed for over 35 years, and we have learned a lot about how some brain diseases may be passed from one person to another in that time. Following the outbreak of 'mad cow' disease in the late 1980s and its human form, new variant Creutzfeldt-Jakob disease (vCJD), much has changed in medical practice, particularly if it's thought that someone might have CJD.

Although the research doesn't suggest that Alzheimer's disease is contagious, it has led experts to call for more research and to advise that all surgical tools be cleaned and blood transfusions be screened even more carefully.

See alzheimers.org.uk/research to find out more about our research work.

Protecting people with dementia

Alzheimer's Society has met with the Care Minister Caroline Dinenage and other politicians to call for people with dementia to receive better legal protection in England and Wales.

A bill being debated in the House of Commons would amend the Deprivation of Liberty Safeguards, which aim to protect people who cannot consent to care arrangements in a care home or hospital that may deprive them of their liberty.

Alzheimer's Society believes the current system is overly complex and offers weak protection of human rights. We want to ensure that any new system works for people with dementia by ensuring there are appropriate safeguards in place.

Say yes to health checks

According to NHS figures, fewer than half of people aged over 40 in England have taken their free health check, which includes advice on reducing the risk of developing dementia and other conditions.

The 20-minute assessment can tell you whether you're at higher risk of health problems, and people in England aged 40–74 are invited for one every five years. If you're over 65, you'll also be told signs and symptoms of dementia to look out for.

James Pickett, Head of Research at Alzheimer's Society, said, 'We welcomed the addition of dementia to health checks earlier this year, building on our work with the NHS and government to improve dementia diagnosis rates, so it's disappointing that so many people are not attending these assessments.'

'Alzheimer's Society researchers are working tirelessly to find a cure but, until that day, we can keep our bodies and brains healthy to reduce our risk of developing dementia.'



Anniversary animation

The Society turns 40 this year and we have launched an animated video celebrating our achievements over the years. Voiced by actor Hugh Bonneville, it also explains our continuing work and ambitions for the future.

Since 1979, the Society has reached a huge number of people with our services, changed the conversation on dementia, invested millions in research and campaigned hard for people affected by the condition to have the support they deserve.

Over the next 40 years we will provide simple, universally accessible support for everyone affected by dementia, and we will find the answers that help us understand dementia better through research.

Watch the animation at alzheimers.org.uk/40thanniversary



In briefs

Social care petition

The 3 Nations Dementia Working Group (3NDWG) has launched a petition calling for a government debate on gaps in social care for people affected by dementia.

The 3NDWG is a network of people living with dementia in England, Wales and Northern Ireland who aim to use their personal experiences to become the 'go to' group for anyone seeking input from people with the condition.

See www.3ndwg.org/campaigns

Annual conference: Book your place

Registration is open for Alzheimer's Society's Annual Conference. Titled The Dementia Priority – local and global action, the event will take place on 21–22 May at the Kia Oval in London during Dementia Action Week.

By taking part, people affected by dementia will be able to share their experiences and have their say alongside those working in health and social care, local and national government, policy and research. Key topics will include dementia and human rights, preventing dementia, and health and social care.

For the full programme and to register, visit alzheimers.org.uk/conference

In their own words

Our magazine audio interviews have been listened to over 10,000 times and counting. The recordings, which can be played online or downloaded for listening later, mean you can hear people with dementia tell their stories in their own words.

To listen, visit alzheimers.org.uk/podcast

Dementia and cancer carers

Talking Point, our online community, has introduced a new area to support carers of people who have both dementia and cancer.

The new section, part of a Leeds Beckett University research project, will provide carers with a place to share practical and emotional support with other people who understand the unique challenges they may face. There will also be tailored information and Q&A sessions with experts.

Join Talking Point at alzheimers.org.uk/talkingpoint



Guide for carers

A brand new version of our guide for carers – Caring for a person with dementia: A practical guide (600) – is now available for free.

The guide helps carers to understand dementia and how to support a person living with the condition. It also gives them advice on their own rights and looking after themselves.

A number of carers were involved in revising the guide, as were health and social care professionals.

Visit alzheimers.org.uk/carersguide or call 0300 303 5933 (local rate) to order a guide.



Be part of Ready Steady GLOW

Memory Walk is taking a step in a new direction for 2019 with a series of walks at night. Ready Steady GLOW is taking place in London on 1 March followed by Manchester and Bristol, both on 2 March.

You can unite under the stars with friends, family and hundreds of others to raise vital funds to support our work. There are also exciting opportunities to volunteer and help make Ready Steady GLOW a night to remember.

Sign up to walk or volunteer at memorywalk.org.uk



Quick read

Nicky Stephens, diagnosed with Alzheimer's in 2014, is determined to remain as active and independent as possible.

Following the sudden death of his husband, 71-year old Nicky has been striving to do as much for himself as he can.

Nicky, who lives in London, enjoys weekly dance lessons as well as a local activity group.

He had a film made about his life to help him reminisce and share his experiences.



Hear Nicky's story

Listen to this and previous stories at alzheimers.org.uk/podcast

Life's rich tapestry

As he tackles both bereavement and dementia, Nicky Stephens remains determined to maintain an active lifestyle. Gareth Bracken meets a man who prefers support to sympathy.

Whether designing furniture, playing in a punk band or learning to dance, Nicky Stephens's life has always been rich in variety. Despite now living with dementia and the loss of his husband, the 71-year old Londoner intends to keep living as fully as he possibly can.

Teacher to punk

Having completed art school in the late 1960s, Nicky trained to become a teacher but left the profession less than a year later after deciding it wasn't for him. A job working as carpenter and joiner for a building contractor then helped him to hone his craft before launching his own venture.

'The boss thought I should stay and was rather annoyed when I said I think I'll just do it myself,' recalls Nicky, who lives in Peckham in south-east London.

He made a success of designing and making bespoke pieces such as furniture, shelving and staircases for private clients.

'I just started finding people who wanted something in their house. Then it got more and more fun because I was designing all sorts. That's what felt really good for me.'

Nicky and his older brother Roger were also in a punk band called The Desperate Bicycles. The group released a series of independent records in the late 1970s and was championed by BBC radio DJ John Peel.

'We all had our own special songs about our lives that we sung,' says Nicky. 'My particular one was about not wanting to be a teacher! It was good fun.'

Syrian connection

Nicky's family includes many high-profile figures with their own fascinating stories. His father, Robert Stephens, was a diplomatic correspondent and foreign editor for The Observer newspaper.

Barbara Altounyan, known as Taqui, was Nicky's mother. She was an inspiration for the author Arthur Ransome, who based aspects of his children's classic *Swallows and Amazons* on his experience teaching her and her siblings to sail in the Lake District.

Taqui, of Armenian, Irish and British descent, wrote two celebrated memoirs of Syria, where she lived and worked at different times. Nicky feels a strong connection to the Syrian city of Aleppo, which he visited with his late husband, Carlo.

'I like to go everywhere but particularly there – I'd like to be there again,' he says. 'Luckily I managed to take Carlo there twice before the terrible things that happened with the civil war. He was very happy to see where I'd been.'

Nicky and Carlo had been together for 37 years when Carlo died suddenly in April 2017. They

had met while celebrating New Year's Eve 1979 in London, when Carlo, an American, was over with the US Air Force.

'He saw me looking at him, so I managed to get to him and we talked,' says Nicky. 'But at one point it was so packed that we lost each other for nearly half an hour and I thought, "Oh no – please!"'

'Carlo was very intelligent and very good at cooking.'

The right words

Having suspected for some time that something wasn't right with his own health, Nicky was diagnosed with Alzheimer's disease in the summer of 2014. One of his most vivid recollections of the aftermath is breaking the news to an old school friend.

'I remember kissing her and saying, "Well, I've got Alzheimer's – I don't know what I can do about it." I didn't really know what would happen. Obviously, gradually I found out more about it.'

Nicky's memory isn't as good as it used to be and he sometimes struggles to find the right word during a conversation. Despite these challenges, he has made a point of remaining as independent as possible.

'I've been determined to do as much as I can myself, because I don't want people to say, "Oh we'd better look after him," and all that stuff,' he says.

'It's very nice but I don't want people worrying and saying, "You can't do this, you can't get the bus." I'm still managing to do a lot and I'm very active, which I think helps.'

However, Nicky acknowledges there are instances where he needs additional support.

'I'm careful not to get into a difficult situation. I accept that there are things my brain finds a bit difficult, and I don't want to get in a state of panic,' he says.

'If I were going on a long train journey north to see my sister, I'd get someone to tell me how to do it.'

A support worker visits Nicky two evenings a week specifically to cook with him, and a woman has been living with him temporarily as part of a homeshare scheme – where a person who needs help to live independently at home is matched with someone who needs accommodation and can provide support in return.

Nicky also attends weekly counselling sessions, and he is grateful for the help he's received from his three siblings.

Finding a way

Nicky's weekly schedule includes a trip to the Royal Opera House in Covent Garden for a dance class for people in the early stages of dementia.

'It's been very good for me. The woman doing it reckons I'm the best one!' he laughs.

At his local Daffodil Activity Group, run by the Society, Nicky takes part in drawing, painting and yoga, as well as helping the sessions to go smoothly.

'I'll put all the chairs out, move things around, do some cleaning up,' he says. 'I'll talk to people – it's quite difficult for some of them but we'll have a talk.'

'The staff there are great, I get on with them. I feel like I'm helping people and they're helping me as well.'

Losing Carlo, in addition to the progression of his dementia, has forced Nicky to come up with new strategies for managing daily life.

'It was easier for me because I had Carlo. It's more difficult now I'm on my own,' he says. 'I have been forgetting things a bit more recently but I'm determined to keep on, so I try and write things down to remind myself.'

'I want to find ways that help me if I'm not doing things quite right. Maybe there are other ways I can keep at it – I'm always looking into things.'

Film to remember

Another source of support, and pleasure, is the film that Nicky had made about his life. It was created by My Life Films, through a free service to help people with dementia celebrate and remember their lives (see www.mylifefilms.org or call 020 8948 7560).

Covering Nicky's childhood through to the present day, the film includes clips of him

reminiscing and personal photographs from over the years.

'My sister suggested it, and I was very keen to see something about myself that helps me to remember,' he says.

'Quite a lot of people who know me have wanted to see it. When I first got the DVD, a group of friends watched it – they seemed to like it. One of the staff from Alzheimer's Society came over to watch it, which was nice.'

'I felt good that I was talking about my life and history. I was quite surprised I managed to do it, I must say!'

So how does Nicky feel about life at the moment?

'It's not bad, it's changed very much,' he says. 'I'm still in tears about Carlo sometimes, but because I'm having to do things myself I'm more active and talk to more people, which I like.'

Nicky is resolute about retaining his independence for as long as he can, and he also wants to see improved treatments for people living with dementia.

'I just hope that one day they'll start working out ways of making it better,' he says.





Next steps

- For our Keeping active and involved (1506) booklet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- For our LGBT: Living with dementia (1511) booklet and Supporting a lesbian, gay, bisexual or trans person with dementia (480) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- For more about homeshare, visit www.homeshareuk.org or call 0151 227 3499.

Fighting for better

As we mark 40 years of the Society, we speak to the campaigners working to end injustice for everyone affected by dementia.

After four decades of campaigning, Alzheimer’s Society has 135,000 e-campaigners, along with many more campaigners on the ground in local communities. They give a political voice to our cause by signing petitions, attending events and sharing their support on social media.

‘Our campaigns ensure that the views and opinions of people affected by dementia are heard at the highest levels of government, so that those in power address the issues that people face,’ says Ele Yorke, Campaigns Officer.

We’ve had numerous campaign successes since the Society was formed in 1979, but recent ones include the Welsh Government’s development of a Dementia Action Plan and NHS England’s call for every hospital trust to publish an annual ‘dementia statement’.

No exaggeration

Our Fix Dementia Care campaign, which has previously focused on homecare and hospitals, is now demanding an end to the injustice that people face across social care. This includes the scandal of people with dementia paying more for their care than those with other conditions. We want a system that works for everyone affected by dementia, and nearly 150 MPs have pledged their support so far.

Sandy Sweet, a campaigner whose mother has Alzheimer’s, spoke to the Prime Minister at last year’s Conservative Party Conference about how difficult it is to access quality dementia care at an affordable price.

‘It’s important that people realise we are not exaggerating the problems people face, as unless you’ve been there yourself it’s difficult to understand the issues,’ says Sandy.

‘Everyone needs to know that, as things currently stand, you will have to pay more for your social care, you may be looked after by people who have no training in your condition and you may struggle to access funding that you are entitled to, simply because of the complexities of the system.’

Stand up

Hilary Doxford, 59, was diagnosed with early-onset dementia in December 2012. Campaigning with us, she met Jeremy Hunt several times when he was health secretary to make sure he understood the changes that are needed.

‘If people don’t stand up and do something, nothing will change,’ says Hilary. ‘I don’t feel I can sit back and watch others do it. I want to give something back while I can.’

‘So many people with dementia can’t voice their opinion, so it’s very important that these campaigns speak for them. It also reinforces the campaign if people with dementia can be part of that voice.’

With the support of our campaigners, we will continue to pressure the government to fix dementia care for good.

‘In another 10 years, it is unlikely that there will be anyone living in the UK who isn’t touched by dementia in some way or another,’ says Sandy. ‘Everyone should get involved with this campaign, whether they are currently affected by dementia or not.’



Talking to politicians at conferences helps us get our message across.



Join our campaign to Fix Dementia Care at alzheimers.org.uk/fixdementiacare – see page 15.



I can, I will, I am

A supporter in Hereford with dementia is running this year's London Marathon as part of the Dementia Revolution to fund groundbreaking research.

For those of us daunted by the idea of one marathon, the extent of Malcolm Brookes's running is hard to truly grasp. Four years ago, he completed his 100th marathon aged 74 – the oldest anyone has been on joining the 'UK 100 Marathon Club'.

Less than six months later, Malcolm was diagnosed with vascular dementia, yet he's run another 15 marathons since then. Training for this year's Virgin Money London Marathon, he's now joined Dementia Revolution – our partnership with Alzheimer's Research UK to fund dementia research that will change lives.

'Running marathons cheers me up. After about two miles, a big grin steals across my face,' says Malcolm.

'My mantra is all positive – 'I can, I will, I am'. Particularly near the end of a race – the last six miles – it's sheer determination. I say, "Bring it on!"'

Hooked

Malcolm, a retired Methodist minister who now lives in Hereford, says he started running marathons 'almost by accident'. His first was in Jersey while working there, and his second 22 years later during a family visit to Portland, Oregon.

'Much to my amazement, I was only seven minutes slower than before.' That's when he 'got the bug'.

'I spotted the 7x7x7 Challenge – seven marathons in seven locations in seven months. I'm a Yorkshireman and I like a good deal, and there was a big discount if you signed up for all seven!

'It was really tough – I didn't know what I'd let myself in for – but after that, I was really hooked.'

Helping

Malcolm is determined to keep active despite the impact of his dementia.

'Dementia has slowed me down. My memory is not as good as it was. I have a laugh at myself – if I'm struggling to find a word I just make up my own one.

'After I was diagnosed, the consultant said carry on running and eat well. I've never had to pull out of a marathon because of dementia. I will carry on for as long as I can do it.

'I've struggled with depression since I was a teenager, but when I'm running I just get into my body and I can get into the physicality of it. It's great, it gives me a buzz – we're all very different!

'If I'm running for charity, I'm helping someone else as well.'

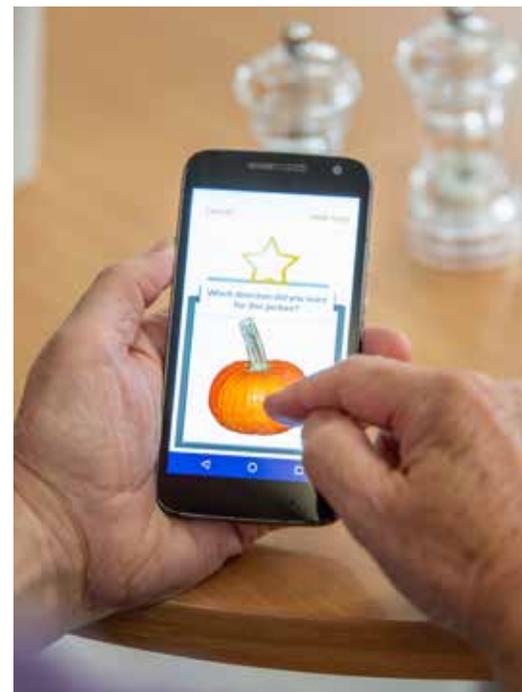
Join the Dementia Revolution and help power groundbreaking research to tackle dementia – find out more at dementiarevolution.org

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

Be a GameChanger



Help us to understand more about how the brain works, and so fight dementia, through GameChanger by playing fun, interactive daily brain games for a month using a smartphone app. Anyone over 18 who doesn't have a dementia diagnosis can join in.

Sign up at alzheimers.org.uk/gamechanger

Side by bedside

A Dementia Friend in Northern Ireland talks about volunteering for Side by Side in a unusual setting.

When Pam Moses, in Crumlin, County Antrim, first joined an innovative Side by Side service at a local hospital, her reservations were understandable.

‘My father and father-in-law both had dementia at the same time,’ she says. They were in care homes at the same time and died on the same day.’

As their dementia progressed, her father was often weepy and emotional, while her father-in-law’s behaviour could be challenging. Even with Side by Side’s excellent training and support, volunteering in a unit for people with dementia who need months of intensive assessment was likely to recall difficult memories.

‘After going in the first time I wasn’t sure, because it reminded me of Dad,’ says Pam, aged 70.

However, it quickly became clear that she had found a powerful way to draw on her passion to make a difference.

‘My husband says he never sees me get up so fast as on the days that I volunteer on the ward!’

Amazing place

Side by Side volunteers usually support people with dementia in the community, helping them to continue doing whatever gives them joy in life. The service in Northern Ireland’s Northern Trust area takes that support into two hospitals.

One, Holywell Hospital, has a unit for people with dementia who are experiencing significant problems, ranging from personal care issues to behaviours that challenge.

‘I thought that volunteering at Holywell might be a little scary because of the stigma of the hospital,’ says Pam, ‘but being on the ward, I can honestly say that’s not the case – it’s an amazing place. It’s a privilege to spend time with the patients.’

In partnership

Volunteers work in partnership with ward staff, who help them identify who would benefit from one-to-one or group activities that day.

Pam says, ‘We do lots of talking, singing and crafts. A few are farmers, and I’m from a farming community so I take a farming magazine in.’

For people who can walk about, photos on the ward’s walls prompt memories.

‘They’ll stop with me at the pictures and we’ll talk about the places in them.’

Even patients with very advanced dementia enjoy hand massage.

‘One lady loves that I rub her hands. She can be quite aggressive, but it calms her down. I’ll ask her if she likes it and she’ll nod her head.’

For Pam, this kind of feedback makes the challenge more than worthwhile.

‘If a loved one of mine was in Holywell, I’d love a volunteer to come in and spend time with them.’

Pam (left) with fellow volunteer Maureen Busby.



See if Side by Side is available near you at alzheimers.org.uk/sidebyside

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

Fix dementia care

Katie Bennett, Campaigns Manager, shares why it's more important than ever to join our Fix Dementia Care campaign.



It's an injustice that access to care depends on your diagnosis rather than your needs. Get diagnosed with cancer or heart disease and you'll be looked after by the NHS, but develop dementia and the situation is starkly different.

People with dementia pay more for essential care than those with other conditions. One in three home care workers have no dementia-specific training, despite people with dementia being the foremost users of social care.

Our Fix Dementia Care campaign is fighting for reform of the social care system to end this injustice – we want high-quality dementia care that's paid for in a fair way and easy for people to access.

The government's plans for social care reform are due out early this year, having been delayed several times already. We'll make sure that dementia is high on the agenda, especially during this time of real political uncertainty.

In the lead-up, we're ensuring that the voices of people affected by dementia are heard across government. As well as pressing the urgent need for social care reform with the Prime Minister, ministers and shadow ministers, we've been talking to politicians at party conferences and other events so that they understand why things need to change now.

We really appreciate the actions that our supporters take to campaign locally and nationally – thank you all! Your continued involvement in the coming year will be vital so that we can carry on putting pressure on the government to Fix Dementia Care for good.

Join our campaign at alzheimers.org.uk/fixdementiacare



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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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.





10 years of song

A Singing for the Brain group in Beaconsfield, Buckinghamshire, that has been meeting weekly since 2009 celebrated its 10th birthday in January.

Special guests included the health campaigner Fiona Castle OBE and local mayor Anita Cranmer, both pictured with Sophie Kelly – the granddaughter of two group members, who baked a cake to help mark the event.

Sally Pierce, who volunteers at the group, said, 'To continue with an activity that my partner Roy used to enjoy is a great comfort and pleasure. Seeing how it helps successive groups of people is enormously uplifting. I feel that I gain more than I give when volunteering.'



Plunge for the cause

Staff from a care home in Bridgend, south-east Wales, united with residents' relatives to raise over £1,200 by taking a bone-chilling dip in the sea on Boxing Day.

The team from Albert Edward Prince of Wales Court in Porthcawl braved the winter waves at nearby Rest Bay, sharing a video of what they called 'The Plunge' afterwards on Facebook. Many donned Santa outfits and a couple of elves were also spotted alongside a large inflatable pink flamingo.

A massive 'Diolch!' to everyone involved, especially to Amanda Kilpatrick-Evans and Hannah Hutchinson, the RMBI (Royal Masonic Benevolent Institution) care home staff who organised the event.

Dare to dream

Flakefleet Primary School in Lancashire may not have made it to be Christmas number one, but they won over the hearts of many with their charity single, Light up, over the festive season.

The Fleetwood school, recognised as the country's happiest primary school in last year's National Happiness Awards, gained a huge amount of press coverage for their song, which was written by pupils and staff.

Complete with a video filmed at a local care home, Fleetwood Hall, the song raised awareness and funds to fight dementia, and included the inspiring lyrics, 'Light up someone's Christmas and you might just light up your own.'



Dementia-friendly Junction

The Junction in Antrim has been working with us to become the first dementia-friendly shopping centre in Northern Ireland.

Many centre and retail staff have taken part in dementia-friendly community workshops, and each store has someone nominated to assist customers with the condition who may need help.

Centre Manager Leona Barr said, 'We have spent time with members of the public who have been diagnosed with dementia to understand exactly how we can make the centre more accessible. We will continue to make further adjustments based on further feedback.'

Pamela Frazer, Dementia Friendly Communities Support Manager at the Society, said, 'From increasing signage to staff wearing a Dementia Friends badge, small changes can make a big difference to people living with dementia and their families.'



Help create a world without dementia

Working at Alzheimer's Society, you'll make a real difference to people's lives. Discover where you fit in, explore the range of career opportunities available to you and sign up for job alerts.

To view all our current vacancies please visit jobs.alzheimers.org.uk

Alzheimer's Society operates in England, Wales and Northern Ireland. Registered charity number 296645

'It's such a fantastic place to work, not only because of the life changing work that we do to enable people to live well with dementia, but the positive atmosphere that exists in the office.'

Will, HR Service Team Leader



Time to talk

Having received strong family support after his wife developed dementia, Pratap Sanghrajka wants others affected by the condition to be open about their needs. **Gareth Bracken** meets a carer calling on people to speak out.

When his wife Jyoti was diagnosed with dementia nearly six years ago, Pratap Sanghrajka had never heard of the condition. Fearing that other carers may be hiding their struggles, he implores them to share their situation with friends and family.

Always smiling

Pratap, 81, was born and brought up in Kenya before coming to England in 1959 for higher education. He married Jyoti in India in the mid-1960s and spent time both there and in the UK, settling in Cheshire in 1979 with their son and daughter. Pratap was an accountant and office manager, while Jyoti briefly worked in a sewing factory but spent most of her time raising their family.

Jyoti, now 75, was fond of embroidery, gardening, literature and music, and could instantly recognise both Indian and western singers. Known for her intelligence and excellent memory, she followed Jainism, a religion that promotes non-violence. Pratap describes her as a family-orientated person who loved children and being around people.

'She was full of life, always smiling,' says Pratap. 'She was a very caring person who

would keep giving without any expectation.'

It was back in 2012 that the family began to notice changes in Jyoti's behaviour. She started to make the same meal regularly during the week, rather than her usual variety. She was speaking about topics from many years ago that were unrelated to the current conversation, sometimes breaking into songs from her childhood. There were also times when she seemed to experience hallucinations – on one occasion she believed there was a black cat in the room.

Jyoti didn't acknowledge that anything was wrong and refused to visit the doctor. Pratap eventually managed to take her, which led to a diagnosis of dementia – following a brain scan and blood test – in April 2013.

'I never thought she would have a disease,' says Pratap, who hadn't been aware of dementia. 'After the diagnosis I started to know what it is and why it is.'

Feeling helpless

Jyoti, who remained adamant that she was fine, developed unusual habits, including picking up and eating food off the floor, putting soap in her mouth, and placing items from shop shelves into her pockets. She also lost her appetite and later would only eat sweet dishes.

Quick read

Pratap Sanghrajka wants more people affected by dementia to be open about their situation so that they can get the right support.

Pratap, 81, who moved permanently to England from India in 1979, hadn't heard of dementia until his wife Jyoti was diagnosed.

He has received great support from his family, who even insisted he move across the country to be closer to them.

He feels that some people hide their needs, and encourages them to make themselves heard to family and friends.

‘She never previously lost her temper, but if the family told her to eat she would get angry and start shaking,’ says Pratap.

Jyoti’s mobility also decreased and she was having continence problems.

‘Things were changing and it was extremely difficult looking after her on my own,’ says Pratap. ‘I had to look after my own health as well and everything was accumulating. I tried to do my best but I was feeling helpless.’

Pratap, who is hard of hearing, was exhausted, losing weight and becoming depressed. His brother Bharat insisted that he move down to Luton to be closer to him and his wife Prafulla, which Pratap did in early 2015.

Pratap was keen to look after Jyoti at home, but the family eventually convinced him that she should move into residential care the following year.

‘They said what would happen if she falls or goes out in the night and you don’t hear?’ he recalls. ‘So looking at the worst case scenario, I decided to let her go into a care home. I still feel guilty, but I had no choice.’

Tell them

Pratap visits his wife every afternoon, taking her a fresh juice drink that he prepares. As far as he can tell, Jyoti has settled well enough into the care home, though he finds it difficult not having her around.

‘I’m thinking about her all the time,’ he says. ‘I think, “Why is it happening? What will happen now?”’

He credits his family, including his ‘heroes’ Bharat and Prafulla, with helping him during some very challenging times.

‘Their support has been so great at every stage, I can just pick up the phone,’ he says. ‘I’ve had family come from London and Cheshire at midnight to help.

‘I feel lucky in that respect, as I’ve heard about people who are suffering through hell as their family support is nil.’

Pratap feels that anyone caring for a person with dementia or living with the condition themselves is best off making their situation known to family and friends.

‘Be open and tell them, without any hesitation,’ he says. ‘I’m very worried to see people just hiding. If you hide it, you’ll keep suffering. But if you tell them, then some people will realise, understand and be helpful.’

Take action

Although Pratap’s advice applies to anyone, he has noticed a particular lack of dementia awareness among South Asian communities in the UK. He recalls attending a luncheon club where people were upset that Jyoti left most of her food, despite Pratap explaining her condition.

‘People don’t really understand, they just think she’s probably mad, full stop,’ he says. ‘This is one of the biggest issues in our community – they turn their face away.’

Pratap feels this is slowly changing. He and Prafulla attend the Guru Nanak, Ujala and Hindu Mandir Wellbeing Clubs in Luton, where people can socialise, enjoy a hot lunch and even do some exercise.

‘They ask how my wife is, how she’s getting on,’ he says. ‘When you tell people she’s in a care home, not talking or recognising us, they realise. They understand and appreciate that this illness is there.’

Pratap is keen to share his knowledge as much as he can.

‘If someone is keen to learn, then I will explain it to them,’ he says. ‘If they are worried about loss of memory, then I’ll discuss it with them.’

He has even shared his experiences on BBC regional TV.

‘There was no difficulty in talking about it. I’d rather speak out and spread awareness,’ he says. ‘I want people to know that if anything is happening to them or their family, they should shout loud or take action.’

Although Jyoti will always be his priority, Pratap also remains dedicated to raising awareness of dementia.

‘It could happen to anyone – you never know,’ he says.

‘I just want to help people as far as I can.’

Pratap with his sister-in-law Prafulla





Photographs: Will Denny

Next steps

- For our publications in a range of languages and formats, see alzheimers.org.uk/accessibleresources or call 0300 303 5933 (local rate).
- Use our online directory to find dementia services near you – go to alzheimers.org.uk/getsupport
- Your fundraising allows us to provide vital support – for ideas, visit alzheimers.org.uk/fundraise or call 0330 333 0804 (local rate).



Better in a crisis

An ambulance call-out can be particularly stressful for people affected by dementia. **Gareth Bracken** reports on a service that's striving to improve experiences.

Quick read

The Welsh Ambulance Service has been working to improve the experience of patients with dementia and their carers.

They have introduced new staff training, while people with dementia have been visiting to assess how dementia friendly the service is.

Andy Woodhead has dementia with Lewy bodies and says he doesn't fear an ambulance coming after his positive experience with paramedics.

Nigel Hullah, who has posterior cortical atrophy, praises how the ambulance service has included people with dementia in their work.

The Welsh Ambulance Service, called out to an increasing number of people with dementia for emergencies and planned transport, wanted to ensure it was meeting their needs and respecting their rights, along with those of carers. It has been making changes based on a Dementia Plan, developed from patient feedback.

'People with dementia expected to receive a timely response in an emergency,' says Alison Johnstone, Programme Manager for Dementia at the Welsh Ambulance Services NHS Trust. 'However they reported poor experiences of calling 999 services and found it difficult to use the telephone to communicate in a stressful situation.'

'We made a commitment to improving their experiences and those of their carers and families.'

Kind voice

The Dementia Plan led to new training for staff, including dementia awareness sessions for those working in the control room, which people living with dementia have helped to present.

Leigh Keen, a paramedic and Dementia Friends Champion, has been delivering Dementia Friends information sessions to paramedics and patient transport staff for the past four years.

'If a person with dementia is unwell or has an infection, the treatment is no different, it's more about communication,' she says. 'It gives our front line staff more confidence – the extra knowledge



might give someone a few tricks up their sleeve to reassure a person with dementia or start a conversation with them.'

Andy Woodhead, who has dementia with Lewy bodies, was treated by an ambulance crew after passing out at home.

'I wasn't the easiest of patients while I was coming to, but the paramedics were brilliant,' he says. 'My carer explained that I had dementia and I think they treated me accordingly. They really took time to make me feel comfortable, not agitated.'

'They were aware of the problems that dementia can cause. Fear is a big problem, and anxiety. And you do become very agitated. I think spending time just calming me down made a big difference. It was just lovely to hear a kind voice – that was worth more than a million pounds to me.'

'I don't fear an ambulance coming now. I don't live with that, because of the good experiences I've had in that situation.'

Dementia friendly

People affected by dementia have also been visiting ambulance stations and contact centres to give their opinion on how dementia friendly they found

the vehicles, equipment and environment. They have also met with call handlers and senior management.

Recognised by Alzheimer's Society as working towards becoming dementia friendly in October 2017, the Welsh Ambulance Service was named Dementia Friendly Organisation of the Year for larger organisations at last year's Dementia Friendly Awards.

Its Dementia Plan has also created a better process for patient referrals and stronger partnerships with other services.

Leigh was involved in a trial, now in practice across Swansea, where ambulance staff could refer patients who they thought might have dementia but who hadn't been diagnosed.

She says, 'They'll check them out and have a conversation. If something isn't quite right, or the family mention something, the staff member can carry out a memory test. If they still have concerns, they can refer the person to our acute clinical team and start the ball rolling to getting a diagnosis.'

Strong voice

A special Dementia Taskforce has been created to ensure the

Dementia Plan continues to develop and deliver. It includes Dementia Friends Champions, ambulance service staff and patient representatives.

Nigel Hullah, who has posterior cortical atrophy, is a member of the taskforce and was also part of the call handler training.

'The taskforce saw that it wasn't about how to solve us – the people with dementia – as a problem,' he says. 'It was about engaging with us and giving us a voice in all parts of the process. Our contributions were valued and acted on.'

The ambulance service has also produced a communication guide for staff and volunteers to aid their interactions with people with dementia. This was created with Society-facilitated groups of people with dementia who meet to have their say on local and national issues.

'We continue to talk and listen to people affected by dementia so they can have a strong voice in our plans,' says Alison. 'Patient expectations and experiences drive improvement across our services.'

'We are so proud of the positive impact our work is having on people living with dementia and their carers.'



Next steps

- Visit alzheimers.org.uk/dementiafriendlycommunities for information about dementia-friendly communities.
- For our dementia awareness training for emergency services staff, email dementiatraining@alzheimers.org.uk or call 01904 567909.
- For opportunities to use your experience of dementia to help shape our and others' work, see alzheimers.org.uk/yoursay

Love to move

Seated gymnastics can help thinking skills, balance and co-ordination. Gareth Bracken visits a class where people affected by dementia enjoy the mix of company and activities.

Quick read

Love to Move is a seated gymnastics programme designed to improve the physical and mental wellbeing of people affected by dementia.

Specialist sessions are held within the community and in care homes, tailored to the needs of participants.

An attendee in Cambridgeshire, 82-year old George Burch, who has Alzheimer's, says the class stimulates him and keeps him going.

Maria, whose husband Terry has vascular dementia, says group leader Kim has the understanding and personality to help Terry feel secure.

A seated gymnastics programme is helping people affected by dementia to maintain their thinking skills and physical co-ordination in a fun, active way.

Love to Move, developed by the British Gymnastics Foundation and funded by Sport England, offers specialist classes within the community and at care homes, tailored to those taking part. This includes people with dementia and people with Parkinson's.

'My mum has advanced dementia and I've felt quite abandoned, so my main aim is to connect with everybody in the class,' says Kim Hall, Lead Programme Coach. 'In the later stages, to get someone to notice you and smile – that to me is important.'

At today's session, Kim and her friendly team of volunteers greet people with dementia and carers at Crossways

Christian Centre in St Ives, Cambridgeshire.

After some relaxed reminiscence, facilitated by the local Norris Museum, everyone sits in a large circle ready for the main event.

Powerful session

The atmosphere is warm and sociable as Kim leads the group through a series of exercises, all set to music. They include drawing letters of the alphabet in the air with a finger and calling out Christmas-themed words that begin with each one.

Kim has everyone clapping their thighs and shoulders to a particular pattern, or moving their arms in time with the music, with some participants using additional weights.

A co-ordination challenge sees the class attempt to draw a circle with one hand and a straight line with the other, with volunteers ready to assist anyone who needs a bit of help.



Chairs are turned side-on as people pair up to play 'one potato, two potato' before the main circle is formed again for a run-through of the hokey cokey. The session is brought to a close with a smiling rendition of We wish you a Merry Christmas.

'People are improving their ability to co-ordinate and we are enabling them to maintain skills,' says Kim.

'People with dementia can be isolated, losing confidence and self-esteem. Working in a group with other people makes it a powerful session in that way.'

Brighter and sharper

Margaret Ditchfield, 89 and living with Alzheimer's, has been attending for around two years.

'I do it for myself and my body, and I like the people,' she says. 'I'm always curious – I wouldn't say, "I'm not going to do that."'

Her husband Derek, 89, enjoys the social side and has benefitted from chatting to other carers.

'You pool your knowledge of how to deal with the situation,' he says.

The couple's daughter, Janet Reindorf, says her parents seem 'brighter, sharper and uplifted' after attending the group.

Another attendee, 82-year old George Burch, was diagnosed with Alzheimer's eight years ago.

'It helps me keep going. It stimulates me because I've done

something,' he says. 'Otherwise I'd sit at home not knowing what to do.'

His wife Beryl, 79, recommends the session to others.

'It keeps you moving your joints, and using your mind, which is good because as you get older you don't do what you don't have to,' she says.

Nobody judging

Maria, 65, attends the group with her 91-year old husband Terry, who was diagnosed with vascular dementia in September 2015. They previously tried a different class, not tailored to people with dementia, which Terry found stressful.

'In other groups you don't always feel like an individual, but Kim has got the understanding and the personality. Terry has got used to her and feels very secure,' says Maria. 'You also feel like the group understands where you are. Nobody is judging you.'

Terry adds, 'The others are all very friendly, we all seem to get along very well. It's not at all frightening.'

Session volunteer Doreen Armstrong has been with the class since it started.

'I just think it's a really worthwhile thing,' she says. 'People affected by dementia can be the forgotten ones who don't always get a lot of support.'

Real success

Love to Move has been a catalyst for St Ives becoming more dementia friendly, explains retired GP George Smerdon. He is part of the St Ives Dementia Friendly Community Steering Group, set up by former mayor Ian Jackson.

'Ian saw the value of Love to Move and the Singing Café that's also held here, and our work grew from that,' he says. 'No one has been resistant to the idea we should do more for people with dementia in the community – it's been one of those real successes.'

Love to Move is expanding and the British Gymnastics Foundation hopes for it to be available in every county of England by 2021.

Patrick Bonner, head of the organisation, says, 'When people want to train their brains they think of sudoku, but when people want physical brain training, our ambition is that they think of Love to Move.'



Next steps

- For our Exercise and physical activity (529) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- Visit alzheimers.org.uk/volunteering or call 0300 222 5706 (local rate) to find opportunities to volunteer in your area.
- Download Love to Move's booklet with exercises to try at home – see www.britishgymnasticsfoundation.org/lovetomove



A moving thank you, a call for change and messages from social media and our online community.

Letter of the month

Thank you because

My brother-in-law in his early 60s is suffering from Alzheimer's at a rapid rate. His wife recently expressed her anguish at his refusal to have a shower in addition to all the other difficulties with which she copes.

My daughter sent her the following message, which is so poignant that I believe it may be of real value to other carers and something that you might want to include. It is all her own words.

Thank you

I know this doesn't help you at all with what you have to do, but thank you. Thank you for hanging in there. Thank you for your tears, frustration, worry, anger, concern and love for him. It means you care. Thank you because I know if he could, he would thank you too.

Michael Sharman, Suffolk

Congratulations to our letter of the month writer, 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 8 March. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

Grasp the nettle

Over six years ago, my son and I tried to claw back from the NHS some of the thousands of pounds spent on my husband's nursing home fees. We went to a well-known law firm for help, on a no-win-no-fee basis. Three NHS tribunals and six years later, we have got nowhere.

My husband went into a coma when at home and, after revival in A&E, I was told that he must go into a nursing home. I had no choice as it could happen again, and it did three times. I sold my family home to pay for care.

We must change this horrible situation of people using their life savings and selling their home to pay for end-of-life care. We must lobby our MPs and government ministers. Another way must be found to pay for care – we must grasp the nettle and move forward.

Mrs Elma Detheridge, Gloucestershire

Join our Fix Dementia Care campaign to demand change – see alzheimers.org.uk/fixdementiacare

For our When does the NHS pay for care? (813) booklet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Pension credit change

The government is changing who will be able to receive Guarantee pension credit from 15 May. Guarantee pension credit is meant to 'top up' your income to a minimum level if you're above pension age.

At the moment, couples where one person is above pension age and one is below can receive Guarantee pension credit based on the age of the older partner.

However, from 15 May – unless they are already receiving Pension credit – the younger partner will have to claim Universal credit on behalf of both people in order to get this extra income. Universal credit has replaced a number of means-tested benefits for people of working age in many areas.

If you think you may be eligible for Pension credit and one of you is below pension age, ask for a benefits check from your local Age UK or Citizen's Advice and make your claim before the 15 May deadline.

Seen elsewhere...



AliceA expressed why she found our online community – see alzheimers.org.uk/talkingpoint – so helpful:

“ On Talking Point, the practical experiences are brilliant. It helps us get through the ever-changing legislation and practices beyond our control. The practical tips prepare us, but in the moment we are on our own with our own inner resources. When I feel fragile, I come on here and read what others are going through. There is a comfort in knowing at least on here we talk the same language. ”



On Twitter, Dementia Friends Champion Kath Parker Stead celebrated her team at University Hospitals of Derby and Burton NHS joining Dementia Friends:

“ Thanks to my speech and language therapy colleagues @UHDBTrust for becoming Dementia Friends! You are all fab-u-lous! @DementiaFriends @alzheimerssoc #moretothepersonthandementia #livewellwithdementia. ”



When we shared a clip on Facebook of care worker William Boyle singing Nessun dorma for his East Kilbride home's residents, Dolores Lee commented:

“ Just in case anyone doesn't already know, care workers don't just carry out the physical and emotional side of their role – they have skills that go unnoticed and it's beautiful to see videos like this. William Boyle, I applaud you, your wonderful colleagues and all carers for everything you do on a daily basis. You have my utmost respect. ”

Benefits: fewer reviews

People with dementia who receive some disability benefits may not have their claims reviewed as much as before.

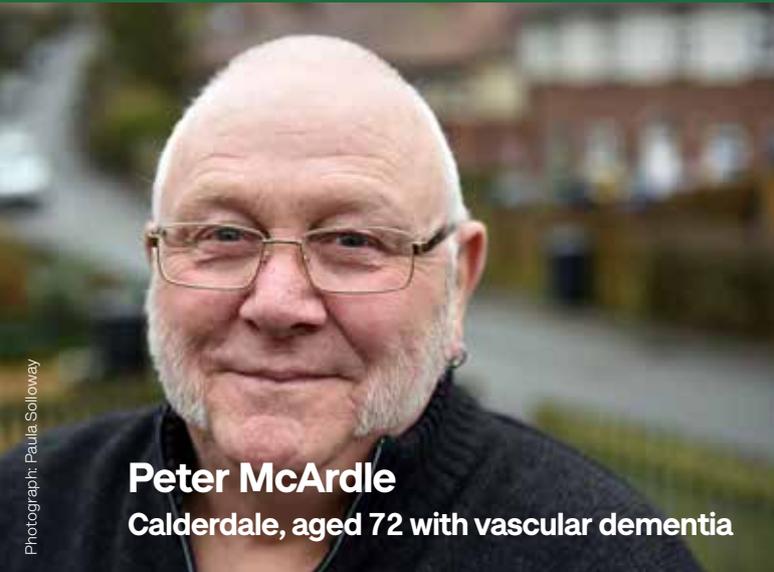
People who get Employment and support allowance (ESA) and Personal independence payment (PIP) have their claims reviewed regularly and this has included people with dementia, even though the condition is progressive.

Since September 2017, criteria to help decide whether a person on ESA can return to work now also refer to people with dementia. Although it's decided on a case-by-case basis, fewer people with dementia may need to undergo repeated assessments to prove their condition isn't improving.

In June 2018, the government announced similar changes for PIP claimants with severe or progressive conditions. Updated guidance says some people could receive PIP subject only to a 'light-touch review' after 10 years.

Alzheimer's Society has been working to make the system fairer by providing information for people conducting assessments about the impact of dementia and we've also been campaigning for them to have better dementia training.

For our Benefits (413) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).



Photograph: Paula Solloway

Peter McArdle
Calderdale, aged 72 with vascular dementia

What's changed most since your diagnosis?
Other people are more aware of dementia than they were five or six years ago, it's more talked about. People who don't have to know anything about it do know a bit now, and that's really helpful.

How has Alzheimer's Society helped you?
There's always somebody who'll take or return your call and who'll listen to you. And the volunteers at cafés etc can't do too much for you – they really do want to help people like myself.

What song or tune sums up your life so far?
The one and only would be Meatloaf's Bat out of hell. I can relate to him, because he's always been at the forefront. I've always liked to know what's happening, the worst and best that could happen – I suppose to have some kind of control. More so with dementia, I read everything there was to do with it, and I've used it to try to help others in the same situation.

If you could go back in time, where would you go?
I'm a great believer that the past is done. But if I had to, then I'd say 1910 to 1914, around the time of the Titanic. I'd want insight into how people really lived then, not what history tells us, to see how people managed. It was just approaching the First World War and the social gap was unbelievable – it would be very interesting.

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.

We visited Ma just before Christmas and met her, along with the northern family, in a local restaurant. She was on good form. Her macular degeneration restricts what she can see, but this didn't appear to bother her – her granddaughter had fitted her with a head torch to help see her dinner!

The next day we met up at the Whitworth Art Gallery, often the scene of Ma's disparaging remarks about exhibited works (she was a painter herself). This time, she fell in love with threadwork tapestries that reflected the journeys and memories of the refugees involved in creating them.

Ma was also inspired by some large stuffed objects on display: 'I want to jump on those, but I better not!'

We spent hours in the café, Ma playing with her baby great-grandson and making a comic face whenever he gently bit down on her finger.

After Christmas, Ma turned 93 and so we rang to wish her a happy birthday and read out cards that had come to us. As ever, she was vague about recent events but happy to share her decided opinions, which can seem strange to us.

She whispered, 'I can't say when your brother's around, but I'm a prisoner here in the back room – it feels like there are bars on the window!'

When she's in one family home she typically says she prefers the other one, but we think this new perception is caused by poor eyesight restricting her view during dark winter evenings. Hopefully it will be resolved when spring arrives!

Dilly, a daughter-in-law
(continued next issue)



Read more from Life with Ma and many other blogs at blog.alzheimers.org.uk



Over 2.5 million
people have become
Dementia Friends.
Will you join them?

Visit
dementiafriends.org.uk
to get involved





People affected by dementia go walking in West Sussex to review a series of nature products.

Exploring nature

It was a consumer panel with a difference in November as we joined a group of people with dementia and their carers on a nature walk. Based in Horsham in West Sussex, the Rusty Brains are part of our Focus on Dementia network – groups of people living with dementia who influence our and others’ work.

To test out some nature packs from Active Minds, available in the Society’s online shop, the group went walking through Pulborough Brooks. The RSPB nature reserve offers views of the South Downs alongside a variety of wildlife.

Pulborough Brooks was a particularly appropriate venue, having previously held dementia awareness days where staff and volunteers took part in Dementia Friends information sessions and met with Alzheimer’s Society staff. It is also planning to make the reserve more dementia friendly, with the input of people affected by the condition.

Nature Walker and Nature Explorer

The group first tried the Nature Walker and Nature Explorer packs, designed to bring the seasons to life and provide people with a goal while they are out walking.

The Nature Explorer series of books, covering spring, summer, autumn and winter, include seasonal photographs to accompany a walk and spark discussion.

The Nature Walkers are sets of reference cards that can be fanned out, containing a range of seasonal textures to search for – turning a walk into an adventure of discovery. You can place objects through a looking hole to compare them with those pictured.

Almost straight away, Beryl found some berries growing and placed them through the hole. ‘Beryl with the berries!’ someone joked.

Jan found both the Winter Walker and Winter Explorer very interesting. She thought the discussion points at the back of the Winter Explorer were a good way of starting a conversation. It was also something you could do indoors or after you’ve come back from a walk.

‘It’s lovely the way the book has been set out – very easy to use,’ she said.

Norman felt the Winter Explorer would be too basic for some people, but acknowledged that it would be useful to many.

Ian liked the Autumn Explorer book, which he was using to identify different types of leaves during the walk.

‘I can recognise leaves without the book, though I didn’t know one or two of them,’ he said. ‘Maybe in a couple of years’ time I might need it more.’

Ian also tried out the Nature Walker for autumn, which he thought would be very good at the right time of year, possibly more for children than some adults.

The Spring Explorer was better than Malcolm was expecting.

‘I was initially concerned about the white background, as I’d expected it to show the animals in their natural habitat, but it actually makes it good for people with dementia,’ he said.

Jenny, who lip reads as a result of hearing loss, was full of praise for the Spring Explorer book.

‘I think this is very good,’ she said. ‘You start with a vegetable, then animal. I would look at the veg and name them. It’s excellent, especially for someone like me when I can’t hear.’

Ian added that it would be lovely to come again in spring and use the Spring Explorer.

Jenny also looked at the Nature Walker for spring, noting that even if a person couldn’t read the flower names on the back page, someone else might be able to help them.

The Explorer books and Walkers usually come as a pair for each season, priced at £12.49 without VAT. Norman felt this was a bit expensive and said it would be better if the books could be purchased separately. As a result of this, our online shop is making them available to buy individually.

Bird Book and Bird Feeder

The Bird Book contains 10 illustrations for birdwatching in the garden or while out on a walk. It could encourage conversation or help people relax as they watch the birds.



Alan, Norman and Beryl all liked the book. 'It's good – it has a short bit of reading on each bird,' said Alan, who was reminded of the sparrows he sees in his garden at home. He also reminisced about his time living in south London, where the bird was so common that they called the local newspaper the Southwark Sparrow.

A Bird Feeder can also be purchased along with the book, as part of a Bird Watcher Bundle. Although the group didn't build the feeder on the day, Norman and Beryl agreed to take it home and try it out.

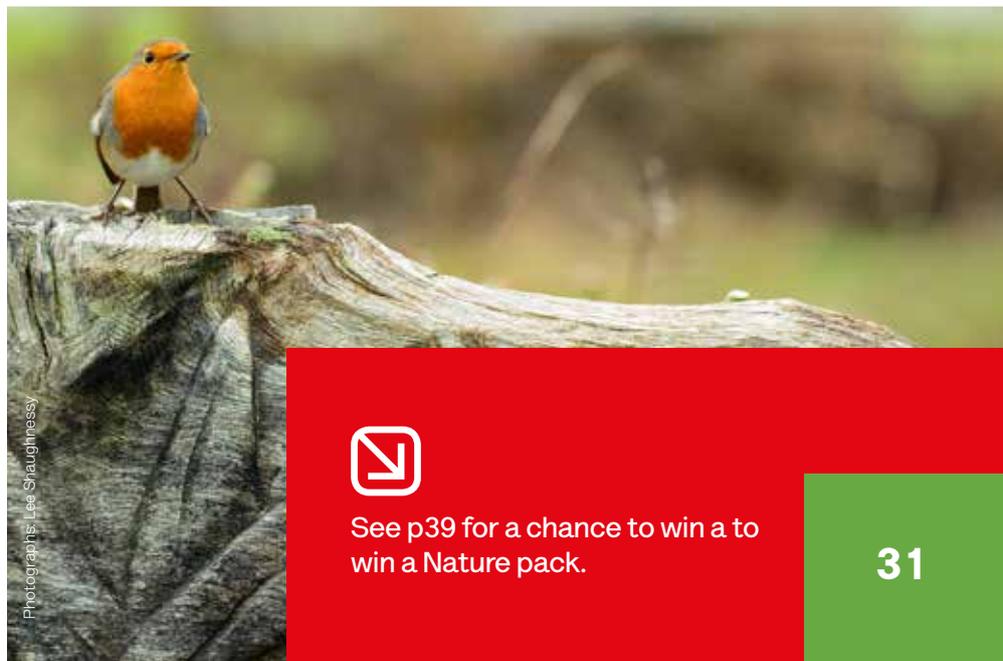
They, along with Jan, liked the look of the feeder and, having taken the pieces out of the box, felt that it appeared simple to set up and use.

'It's better than the one we've got, where all the birdseed falls out!' said Norman.

Of these products, even those that would usually have VAT on them are exempt if bought for a person with dementia or other condition. If so, then each Nature Walker is £9.58 and each Nature Explorer is £3.49. The combined Nature Explorer and Nature Walker packs are £12.49. The Bird Feeder is £10.83, the Bird Book is £6.99 and the Bird Watcher Bundle is £16.66.

As well as helping our online shop know what's most useful to stock, the group's feedback will also be shared with suppliers.

For these and many other useful aids and gifts, see shop.alzheimers.org.uk or call 0300 124 0900 (local rate).



Photograph by: Lee Sraughnessy



See p39 for a chance to win a to win a Nature pack.



‘I have dementia and the council has assessed me as needing support at home, but my savings mean I need to find a homecare agency myself. Where do I start?’

Choosing homecare

Finding homecare – also known as domiciliary care – can feel overwhelming. It may be difficult to know where to start, but thinking about the type of care you need is a good first step.

What, when and who

Homecare could involve a combination of personal care (such as washing), preparing meals, companionship, healthcare needs or cleaning and other help around the home.

Think about how often and when you need support. For example, if you need help showering and you like to shower in the morning, it’s important the agency can support this.

Look for local homecare agencies and create a shortlist of two or three. You may want to focus on agencies with experience of supporting people with dementia.

The regulatory body where you live will have details of agencies – this is the Regulation and Quality Improvement Authority in Northern Ireland, Care Quality Commission in England or Care Inspectorate Wales.

The UK Homecare Association can also help – visit www.ukhca.co.uk or call 020 8661 8188 and select 1.

Useful questions

When you contact agencies, you may want to arrange a meeting to find out more about how they work and how you feel about them. Questions could include:

- What training do their care staff have? Would you have the same carer(s)? Can you specify whether you’d like a female or male carer? Can you meet the carer(s) before they start? Do they keep notes, and can you see these?
- Will there be a care plan to meet your needs? How often will they assess your needs? How would they manage a change in needs? Are they able to meet any religious or cultural needs that you have?
- Are their costs based on an hourly charge? Are there a minimum number of hours? Do they charge more for weekends and bank holidays? Are there any additional charges?
- Does the agency have insurance? What is their complaints process? What do they have in place for unexpected events, such as staff sickness? Can you change carers? Is there a trial period, and how long is it?

What next?

Once you’ve found an agency that you’re happy with, you can agree a start date. It’s a good idea to monitor how things are going – you may want to read notes made by care staff and arrange regular contact with the agency.



Find out about other people’s experiences of looking for homecare on our online community, Talking Point – see alzheimers.org.uk/talkingpoint



Talking Point is an online community where people with dementia – as well as anyone affected by the condition – are there for each other.

Your diagnosis, your community

Our online community, Talking Point, is there for anyone affected by dementia, including people with a diagnosis themselves.

Being told you have dementia has a big emotional impact, and talking about how you're feeling can make a real difference. This could be with a partner, friends or family members. However, many find it helpful to share feelings and thoughts with people they don't know, but who get what they're going through.

This is what Talking Point is about, and it's full of people who have had similar emotions and experiences. It's easy to join, you don't have to use your real name and it's there 24/7.

Any subject

Talking Point has a dedicated area for people who have a diagnosis of dementia. This means there's always a place where you know there'll be other people who understand what it's like to live with the condition.

Of course, you might not always feel like talking about dementia, and there are other places on Talking Point where you can talk about more light-hearted topics and share other parts of your life.

Our 'tea room' is an area that's specifically for community members to discuss things that aren't focused on dementia. You can share jokes, join in a word game, tell people about things you've been doing lately, or simply say how your day

has been. Some Talking Point members say this helps them to escape the realities of being affected by dementia for a little while, and to just talk to like-minded people about things they enjoy.

We also have an area for people to share the books, films, TV shows and music that they like or find useful, and another solely for poems.

Always there

Whether you're having a good day, bad day or just a day, you can always share how you're feeling on Talking Point. You are not alone, and our online community brings thousands of people together who will listen and understand.



Join in

Talking Point is free, open day and night, and you only need an internet connection to read conversations and start your own. Visit alzheimers.org.uk/talkingpoint



We hear what readers thought of Christine Bryden's latest book, about what a dementia diagnosis means for a person's sense of self.

Will I still be me?

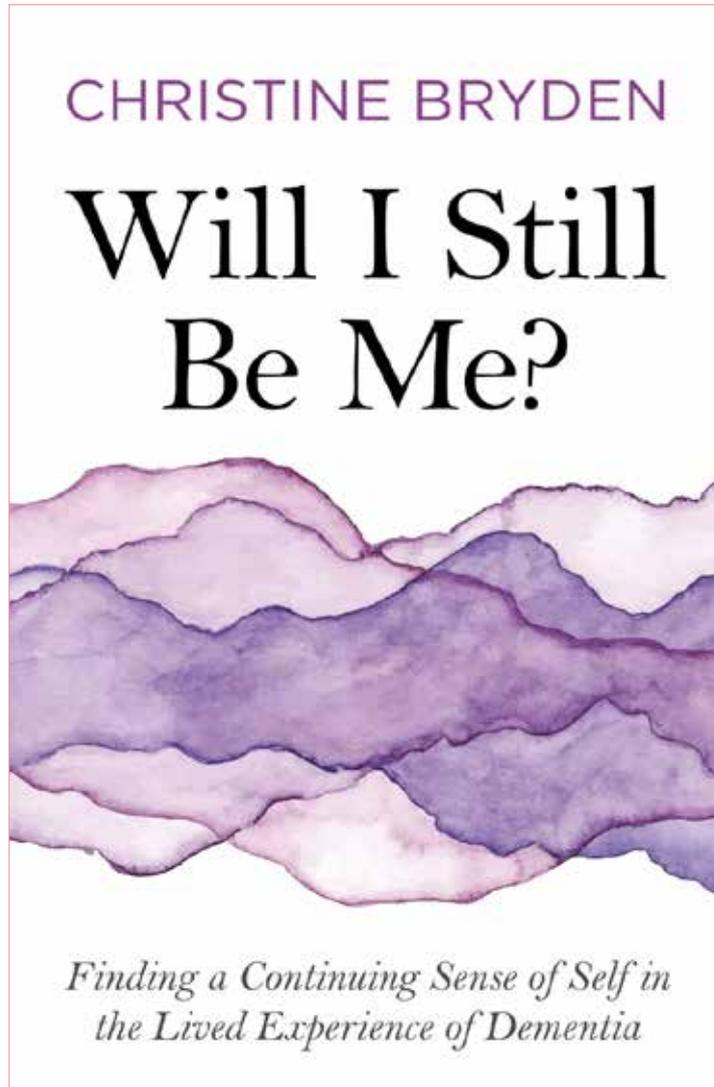
Christine Bryden's first book was published three years after she was diagnosed, in her forties, with dementia. Her most recent – *Will I still be me?* – sets out to challenge assumptions about identity and selfhood in dementia.

Caroline Branney, who manages our Dementia Knowledge Centre, says, 'Christine disagrees with people looking at dementia from an "outside" perspective when they talk about the loss of self, often with many underlying assumptions. We tend to value autonomy, competence and intelligence, and often devalue people who might not be able to demonstrate these.'

'Views of loss of self in dementia lead to stigma, isolation and fear for the future, so that people are even fearful of seeking a diagnosis.'

Keith Oliver, a Society Ambassador living with Alzheimer's, helped us to get the views of fellow members of the Forget Me Nots group in Kent.

Chris says, 'As a person living with dementia and having started reading the book, I initially had my doubts about what was being outlined. Although endeavouring to focus on the things I can still do, I believed that my dementia was diminishing me. I am losing skills that I have had for most of my conscious life.'



'However, I have read the book twice through now and in doing so, I have come to realise that, although I am changing, my basic moral values and beliefs still remain. An alteration of my abilities or change of behaviour may exist, but my awareness of my existence (called "self" by the author) still remains.'

Revealing

Keith says, 'Having read and gained much benefit from Christine's earlier books, I eagerly began to read her latest. The title accurately conveys the book's key themes which I found introspective and revealing, if at times very challenging.'

'I liked her method of combining her experience and views alongside the case studies, which support the book's balanced key messages around one's sense of self.'

David appreciated the book's tone and structure. He says, 'Gathering the experiences of others from various backgrounds and their reflections, and the optimism rather than purely pessimism of change – the book is written with skill and insight. There are metaphors that make me smile and think! It's an uplifting and realistic book.'

Nigel says, 'This is an appealing read for people on a dementia journey, as it makes the case that the sense of self remains throughout. It is well argued and Bryden provides anecdotal evidence in support of her case.'

'She is an inspiration in her continuing career, writing autobiographically to inform those on the journey and their caregivers, and to provide hope and positive encouragement. A good read for all those touched by dementia.'

Tenacity

Keith says, 'I admire Christine's tenacity and academic acumen, which despite living with dementia for 23 years, remain evident and are inspiring for those of us who also live with this wretched disease. A must-read for health professionals working in this field.'

Carol, another Forget Me Nots member, found the book's language too off-putting. 'While excited to review this book, after reading the first chapter I realised it was going to be extremely difficult,' she says.

'I have early onset Alzheimer's and was not surprised by this, as I struggle with language. I struggled with the academic words and phrases so felt I had to give up reading the book, as I couldn't understand what the author was saying.'

Elizabeth, an older people's mental health professional, thinks it's well worth sticking with despite this.

'This book is not an easy read,' she says, 'with frequent citations interrupting the flow of

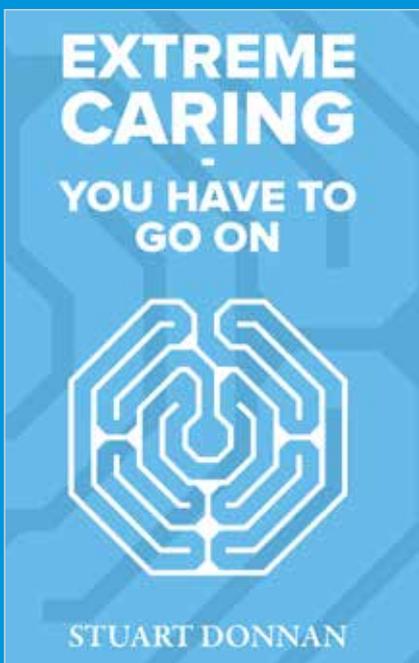
text. However, she raises many important points and highlights the necessity and value of communities including people. This encourages us to continue connecting and relating to people living with dementia, valuing the present moment.'

Chris says, 'The book clearly outlines that, just because we may lose the ability to do things or our cognition is impaired, it does not lessen our right to exist and be acknowledged for the living person that we are.'

'Christine argues her points clearly as an "insider" living with dementia looking out. By reading her book, she has re-instilled in me a sense of worth and value as a member of the human race.'

Will I still be me?

by Christine Bryden
(Jessica Kingsley, 2018),
144 pages, £12.99,
ISBN: 9781785925559.



Your turn

For the next issue, we invite you to read Extreme caring: You have to go on, by Stuart Donnan (DestinWorld, 2016), 252 pages, £9.99, ISBN: 9780995530706.

Let us know what you think about this personal account – of the author caring for his wife after her stroke and later diagnosis of dementia – by 4 March, so we can share it in our next issue. Email magazine@alzheimers.org.uk or write to the address on p3.

We have five copies to give away – email magazine@alzheimers.org.uk or write to the address on p3 by 18 February quoting 'Extreme' for a chance to win one (see p39 for terms and conditions).



Talking Point members share advice about adjusting after a person with dementia moves into a care home.

After the move

'What I did when my mother first went into a retirement home, then a nursing home, was to get to know the staff as well as possible. I am a sociable and chatty person, so it wasn't difficult for me to do so. Having that personal relationship with many staff members was extremely helpful to me. In fact, I once heard one staff member say to another that I was "one of them".

'It is important to realise that the staff are human also, and have their own cares and woes. If they do the best they can, we can ask no more.' **Canadian Joanne**

'I had an Auntie Betty. She was lovely, and much loved. She ended up in a care home in the late stages of dementia. It was many miles, and across the water from me, but I went to see her. There was a new manager in the care home who insisted that all the residents have their names on their room doors. My auntie's room said that she was called "Elizabeth". I was furious!

'I understand that hearing is just about the last sense to leave us when death is approaching. I reasoned that if Auntie Betty had any remnants of the lady I knew, and could hear and make a little sense of what she heard, she would be very lonely, because if they were calling her "Elizabeth" (and they were) she would not recognise herself. I asked them to call her "Betty" and put "Betty" on her door.

'Now, as my loved other half becomes more distant, I hope when or if the time comes, I will be able to give the care home that little bit of information that might tell my other half that he is still loved and not forgotten. The devil is in the detail.' **maryjoan**

'Make use of any respite opportunities there are. It's not cheap, but to know for 24/7 your loved one is cared for, while you can sleep, is worth its weight in gold.

'Know that having to put your loved one with dementia into a nursing home is not failure as a carer. You are doing the best you can for them. You were on call 24/7 and it's exhausting, leading to carer burnout,

mental health issues, stress and associated health problems.

'A nursing home has a team of people on call for your loved one, a member of their staff works a shift and is not there 24/7 like you were. You will find (if the home is a good one) that your relationship with your loved one with dementia improves. After that period of total rest, you will begin to find you, the person before the carer role took over... No guilt.' **Ree 123**

'When Mum moved into her care home I tried to think of it as her having just moved. If she had moved to a flat or even a bedsit it would have been OK, but the fact that it was a care home seemed to make it different. So I never, ever said to anyone (not even myself) that I had "put her in a home", but decided to think of it as Mum having moved to a bedsit with communal facilities and staff around to help her. If I thought of it in terms of Mum just having moved home again, it made it easier.' **canary**

'Mum has been in a nursing home since September, and I have found it difficult to "let go", having to put my trust in strangers to look after her and care for her.

'Getting to know the carers and to share things that Mum used to like doing (or not as the case may be), and to watch the carers interact with her, I can see the carers that Mum likes and those she doesn't – not because they have done anything wrong but for some reason in her head she doesn't like them. I found out the other day that Mum doesn't like one carer because she is tall!

'I can now spend more quality time with Mum, as I am not nagging at her to eat or drink etc, and that is a big bonus that I have accepted gratefully.' **Jale**

Visit alzheimers.org.uk/talkingpoint to read the full thread and join our online community.

Next issue

What advice would you give to make sure a person with dementia who's had a fall gets the support they need? Email magazine@alzheimers.org.uk or write to the address on p3.



Spring-ready garden

Gardening brings great joy and fulfilment to many people. This can continue as dementia progresses, though adaptations may be needed. Preparing for spring and taking advantage of its arrival can provide many meaningful activities.

In February, this could include sprouting seed potatoes so they're ready for planting, pruning winter-flowering shrubs that have finished flowering, and preparing vegetable seed beds. In March, shallots and immature onions may be planted, as can early potatoes and bulbs that flower in summer.

Consider what tools would be appropriate – if a person may not be able to use a tool safely themselves, can they be supported to do so? Think also about whether the plants are poisonous, have sharp edges, thorns or skin irritants. There are often alternatives that an unsuitable favourite could be substituted with. For example, replace Christmas rose, which is poisonous and may irritate the skin, with wake robin (*Trillium grandiflorum*) or barrenwort (*Epimedium*).

For people not as familiar with gardening, the Royal Horticultural Society provides helpful information and advice at www.rhs.org.uk/advice

A person who enjoys gardening but doesn't have access to a garden may like sowing herbs and flowers in indoor pots. These plants could be re-potted as they outgrow their containers.

Many ideas are included in our guide *Taking part: activities for people with dementia*, at a reduced price of £10 plus postage from our online shop – see shop.alzheimers.org.uk or call 0300 124 0900 (local rate).

Selecting and moving into a care home

This booklet is for carers as well as people with dementia who want to plan ahead. It includes:

- checklists of things to look for
- tips for moving in
- advice for handling challenges.

To order your free copy, call **0300 303 5933** or email orders@alzheimers.org.uk quoting code 690.



If you or someone you know has questions or concerns about dementia, we are here for you.

Talk to us

Our National Dementia Helpline can provide information, support and guidance.

Call **0300 222 1122** 9am–8pm Monday to Wednesday, 9am–5pm Thursday and Friday, 10am–4pm at weekends or email helpline@alzheimers.org.uk

Talk to others

Talking Point is our online community for anyone affected by dementia open 24–7.

Visit alzheimers.org.uk/talkingpoint

Find the information you need

Our wide range of publications provide information about all aspects of dementia and dementia care.

See alzheimers.org.uk/publications

Support near you

Search our online services directory by postcode, town or city to find information about services and support groups in your local area. Go to alzheimers.org.uk/dementiaconnect

alzheimers.org.uk
alzheimers.org.uk/facebook
alzheimers.org.uk/twitter

'I can't tell you how much it has meant to me to have good in-depth information. You have made such a difference in our lives.'

Carer





Nature pack

We have a Spring Nature pack for one lucky winner and Spring Nature Explorers for four runners-up drawn from correct entries received by 4 March.

Q: The pioneering Victorian and Edwardian era naturalist who campaigned for women to have equal rights to full fellowship of learned societies was:

- A. Mary Seacole.
- B. Ada Lovelace.
- C. Marian Farquharson.

Send us your answers with your name and address – email magazine@alzheimers.org.uk or post to the address on p3.

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.

Will I still be me? giveaway

The five readers who each won a copy of Will I still be me?, by Christine Bryden, were K Lilley in Essex, L Baker and A Jennings in Derbyshire, E Sargent in Norfolk and J Samuel in Hampshire.

Talking time pal competition

J Gibbs in West Midlands and D McKillen in County Antrim each won a Talking time pal. Answer: The invention of the first machine that could record and play back sounds was claimed in 1877 by Thomas Alva Edison.

Running top

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Back



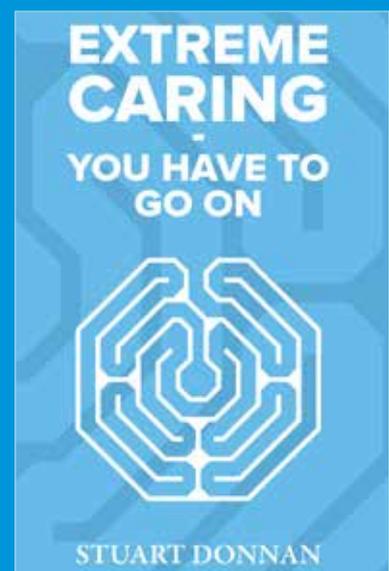
We have an Alzheimer's Society running top for one lucky winner drawn from correct entries received by 11 March.

Q: Records of competitive racing date back to the:

- A. Tailteann Games in Ireland in 1829 BCE.
- B. Olympic Games in Greece in 776 BCE.
- C. First It's a Knockout! series on BBC1 in 1966.

Book giveaway

See p35 for a chance to win a copy of Extreme caring by Stuart Donnan.





Step into Spring!

Our range of nature activity products are designed for people living with dementia. Ranging from nature walks to bird watching, each activity has been designed to help encourage conversation, improve wellbeing, increase engagement and provide stimulation.

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

Shop now

shop.alzheimers.org.uk

