

Dementia together

June/July 2018
Alzheimer's Society's magazine

Source of strength
Fighting back

Smarter policing
Better prepared

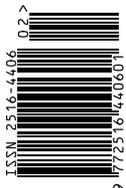


Little visitors
New life in care homes

Also in this issue
Dementia Action Week
Side by Side
New womenswear
Inappropriate behaviour



Strain on the family
Dramatic changes



Become a Dementia Friend

Meet Alex, Teresa and Emma who are living with dementia. Hear about their experiences, how the condition affects their day-to-day lives and what actions you can take to help people like them in your community.



Visit dementiafriends.org.uk
to find out more



Welcome

Welcome to another issue of Dementia together – the Alzheimer’s Society magazine for everyone in the dementia movement and anyone affected by the condition.

We hope you’re looking forward to Cupcake Day on 14 June and ahead to Memory Walk this autumn, both of which are excellent (if very different!) opportunities to come together for the cause.

We’re always keen to hear your feedback and ideas about the magazine, so do let us know using the contact details below.

Danny Ratnaike, Magazine Editor

Inside

News

Dementia Action Week 4



Source of strength
Fighting back 8

Society

World of difference 12
Let’s chat 13
Try something new 13
Spiritual connections 14
A website that offers more 15
In your area 16

Strain on the family

Dramatic changes 18

Smarter policing

Better prepared 22

Little visitors

New life in care homes 24

This is the June/July 2018 issue of Dementia together, the magazine for all Alzheimer’s Society supporters and people affected by dementia.

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Letters 26
Q&A: Jules Emberton 28
Life with Ma 28
New womenswear 30
Inappropriate sexual behaviour 32
Family problems 33
The Songaminute Man 34
Dementia-friendly home 36
Sports and exercise 37
Competitions 39

End the dementia care crisis

Alzheimer's Society is calling for bold reform of a social care system that has abandoned many people affected by dementia.

Our new report, *Dementia – the true cost*, has found that people in England, Wales and Northern Ireland are struggling to access the vital care they need. When they do receive such care, they often face catastrophic costs.

Launched at our Annual Conference in May, the report is based on the first-hand experiences of people affected by dementia, dementia lead nurses and social care professionals.

It calls on governments to commit to reform social care, end the unfairness and deliver the change that people affected by dementia deserve.

The Society's Chief Executive Officer, Jeremy Hughes, said, 'Turning up the volume on dementia can and does make a difference – and we must create enough noise to make our case for change impossible to ignore.'

'This report is a rallying call from the front line that enough is enough. The social care crisis is a dementia crisis and we need bold reform that ends this inequity.'



Dementia Action Week
21–27 May



Small actions.
Big impact.
What will you do?

Take action and unite with us
alzheimers.org.uk/DAW
#DAW2018
Registered charity no. 239042

Dementia Action Week

Supporters across the UK have been uniting in actions big and small to improve the lives of people affected by dementia as part of Dementia Action Week.

Whether continuing to invite a person out, being a bit more patient or including them in conversation, thousands of you have played your part in helping people feel more supported.

Alongside these small but significant individual actions were a number of organised events.

In Richmond, south west London, Alzheimer's Society hosted an exhibition of creative work by people living with dementia and offered a Dementia Friends session for people who wanted to support others in their local community.

The 20:20 United Against Dementia Cycle saw riders in Omagh, Northern Ireland take on 30, 50 and 70-mile routes, as well as a family track cycle, to raise awareness and funds.

Information stands across Wales, staffed by dementia support workers, provided advice and information to people affected by dementia while promoting Alzheimer's Society services and volunteering opportunities.

Pam Roberts, who lives with Alzheimer's and appeared in Dementia Action Week ads, says, 'To everyone who has even taken one small action, I'd just like to say thank you because it's making a big difference.'

Making our point to MPs

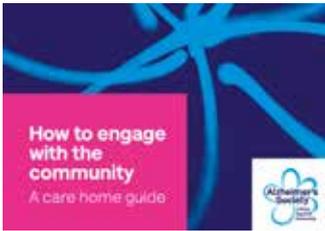
Alzheimer's Society has been delivering our message directly to decision makers in parliament.

We held a special Westminster event during Dementia Action Week where we spoke to MPs about our Fix Dementia Care campaign, our report *Dementia – the true cost*, and the upcoming green paper that will shape the future of adult social care in England. This was a great opportunity to make it clear how they can help improve care and support for people affected by dementia.

We have also been holding Dementia Friends information sessions with MPs, staff from the Department of Health and Social Care and from the Ministry of Housing, Communities and Local Government.

To make sure your MP is showing their support, visit alzheimers.org.uk/campaigns

Connecting care homes with communities



A new resource aims to help care homes become central to their local communities.

The Airedale Social Movement was an Alzheimer's Society project that encouraged community organisations from schools to bowls clubs to run activities with residents in West Yorkshire care homes. This helped

reduce isolation and improve quality of life for people with dementia.

Using the lessons learned from Airedale, the team behind the work has launched a toolkit to help other care homes do similar for their residents.

To access the toolkit visit alzheimers.org.uk/carehometoolkit

Wilko to fundraise for the Society

High street chain Wilko is aiming to raise over £1.5 million for Alzheimer's Society.

As part of the retailer's Together for Families Charity Programme, the Society will receive a share of a £5 million fundraising target over the next three years.

Wilko staff will be taking part in activities to raise money towards local community care services such as dementia support workers.

Wilko's target could fund nearly 80,000 hours of support for people with dementia and their families, alongside 133,200 hours of support from our National Dementia Helpline.

Get involved with Memory Walk

You could be one of over 110,000 walkers uniting against dementia at 41 walks across England, Wales and Northern Ireland this autumn.

Alzheimer's Society is aiming to raise £9 million to support people affected by dementia, with every pound helping us to provide vital information and support, improve care, fund research and create lasting change.

We also need volunteers to make the walks happen. There are many ways you can get involved, from marshalling to cheering on walkers at the finish line and presenting them with their medals.

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

At the beginning of May, it became public that Dame Barbara Windsor has Alzheimer's, having been diagnosed four years earlier.

Being such a national figure, the announcement by her husband, Scott, prompted a wave of publicity, and he readily acknowledged the importance of our support. For me, the media reports highlighted that, whoever you are, no one should have to face dementia alone.

Many people will have seen our awareness campaign and been involved in the thousands of Dementia Action Week activities at the end of May. Of course, we must improve our health and social care systems as a matter of urgency for all people affected by dementia.

Yet we're also reminded that everyone has a part to play in breaking down the isolation that many can feel, and the despair and dependency that can result. Whether as a Dementia Friend, Side by Side volunteer, campaigner, fundraiser or Research Network volunteer, we can all make a difference.

Let's not only make sure that the Queen Vic in Albert Square is a friendly and supportive place for anyone affected by dementia, but that every public place in every community is too.

Jeremy Hughes
Chief Executive Officer



Drug links to dementia

New research has suggested a connection between taking some anticholinergic drugs, which are used to treat a wide range of conditions, and a person's risk of developing dementia.

This Alzheimer's Society-funded research, reported by the BBC, The Telegraph and The Independent, compared the medical records of 40,770 people with dementia aged 65 to 99 to a group without dementia.

The researchers found that some anticholinergic drugs were linked to a person's risk of developing dementia. We've known for some time that they can cause older people to have trouble thinking clearly, but it hasn't been clear whether they may be related to the onset of dementia.

Dr Doug Brown, our Chief Policy and Research Officer, said, 'This large study confirms that some anticholinergic drugs can raise the risk of dementia, but it should put minds at ease that there appears to be no dementia risk with ones used to treat more common conditions like hay fever and stomach cramps.'

'Doctors should consider these new findings for all over-65s, as long-term use could raise the risk of dementia.'

It is important to remember that this study only looked at risk – it cannot show that anticholinergic drugs cause dementia themselves. The researchers believe that the risk to people is low, and if you are concerned about your medication, do not stop taking it until you have spoken with your GP.

Have your say

A group of MPs and Peers from across the main political parties are seeking people's experiences of dementia and their views of it as a disability.

The All-Party Parliamentary Group (APPG) for Dementia is investigating the barriers that people with dementia face in having their rights met, and the impact this has on daily life.

The APPG is hopeful that the inquiry will help create meaningful change for people affected by dementia.

To share your experiences, please visit alzheimers.org.uk/appg



Join the Dementia Revolution

A partnership between Alzheimer's Society and Alzheimer's Research UK has been named Charity of the Year for the 2019 Virgin Money London Marathon.

As part of a year-long Dementia Revolution campaign, the charities have joined forces to raise £3.5 million to power ground-breaking dementia research as we overthrow old attitudes and lead the charge towards a cure.

British marathon legend Ron Hill, who has Alzheimer's disease, is an ambassador for the Dementia Revolution.

He said, 'At the moment dementia can't be stopped in its tracks, but hopefully we can start to change this on the back of the marathon.'

Apply for a marathon charity place at dementiarevolution.org

Scouts support

Scouts across the UK have been putting on dementia-friendly events to support people living with the condition in their local communities.

Among the activities, Scouts in Leamington Spa visited a local care home to sing songs with residents, while Harrow Scouts are holding a 'colour run' – where runners are showered with different coloured powder at points along the race – to fundraise for the Society.

Collectively known as The Big Moment, the events were part of an initiative called A Million Hands, which encourages Scouts to make a difference on big social issues.

To get involved visit www.amillionhands.org.uk or email youngpeople@alzheimers.org.uk





See dementia differently

Alzheimer’s Society is using virtual reality to show people the effects of dementia.

Using a special headset, members of the public watch a virtual reality film that simulates some of the common effects of dementia on a person’s vision and hearing. Once they have been introduced to the experience and impact of dementia, they are asked if they’d like to support our work with a regular donation.

The innovative new approach, part of our See dementia differently fundraising campaign, is being used in parts of the Midlands and north east of England, and at some London train stations.

This exciting new form of fundraising could be expanded to other parts of England, including some Alzheimer’s Society Roadshow sites.

In briefs

Rural dementia guide

Alzheimer’s Society has published advice for creating dementia-friendly communities in rural areas.

People in rural areas often face geographical, financial and transportation constraints that may make it difficult to access advice and support.

Our Dementia-friendly rural communities guide offers community-led guidance and signposting to resources to help support people with dementia and carers to be included in all areas of community life.

To access the guide visit alzheimers.org.uk/rural

Cupcake Day is here

Crumbs! Cupcake Day is just around the corner.

The big day is on 14 June, but you can host any day that suits you.

Don’t miss out on the fun. Rise against dementia by signing up to host a Cupcake Day at work, home, school or anywhere else.

More of a faker than a baker? Not a problem – dashing to the shops for your cakes is just fine by us too!

Sign up for your free fundraising kit at cupcakeday.org.uk

Faith and dementia

People affected by dementia have come together with faith leaders to discuss the challenges they face in continuing to interact with their cultural communities.

Members of Sikh, Christian, Muslim and Jewish communities, among others, met at our Faith, Culture and Dementia Conference in London to understand people’s different needs, discuss solutions and pledge actions.

Harriet Hill, Programme Partnerships Officer at the Society, said, ‘The event celebrated what so many faiths have to offer and enabled attendees to explore how they can better support people affected by dementia to practise their faith. I hope that this event is just the start of the work still to come in this area.’





Quick read

After a devastating vascular dementia diagnosis, Chris Maddocks has rebuilt her self-esteem by immersing herself in the dementia movement.

Chris, who lives in Eastbourne with her partner Heather, has contributed to groups, talks and a Society LGBT+ (lesbian, gay, bisexual and trans) project.

She hopes the Alzheimer's Society LGBT+ project will see us lead the way in promoting a better understanding of people's specific needs.

Chris wants to do what she can while she still can, and says that getting involved makes her feel useful.

Source of strength

After a dementia diagnosis that felt like a 'death sentence', Chris Maddocks is fighting back. Gareth Bracken meets a woman who has vowed to do what she can while she can.

When she was diagnosed with young-onset vascular dementia aged just 60, Chris Maddocks initially thought her life was over.

But with the support of her partner, Heather, she has rebuilt her self-esteem by immersing herself in the dementia movement and doing all she can for the cause.

Alien feeling

An avid player of squash, badminton and tennis in her youth, representing South Wales schools in the javelin, Chris originally thought she would become a PE teacher.

Instead, she joined South Wales Police and spent 30 years in the job, mostly in CID. She also had a five-year secondment to Interpol in London during the 1990s.

Chris, 62, latterly worked in law enforcement for the Environment Agency before retiring because of ill health in October 2016.

She met Heather, now 59, around 12 years ago at a police rehabilitation unit.

'We happened to both be having physiotherapy on injuries,' recalls Chris. 'We kept in touch, remained friends and then started holidaying together.'

Chris, who now lives with Heather in Eastbourne, East Sussex, had three strokes in her 50s, which led to extreme fatigue and memory problems.

After a spell off work, she returned part-time but was struggling to cope.

'I couldn't remember how to get onto my email account,' she says. 'Then I was reading our new policies and procedures and nothing was going in.'

Chris retired from work but daily life was still proving a struggle.

'One day I went to get dressed but couldn't remember how,' she says. 'I sat on the bed for 10 to 15 minutes before it came back to me.'

In the aftermath of her third stroke, Chris also experienced depression and anxiety.

'I was in the local supermarket and felt as though everybody was looking at me – I just had to leave the shop,' she says.

'I don't know why it happens, but you just feel as though you're not coping. I did a very responsible job for 30 years, so it's such an alien feeling for me.'

'Death sentence'

Chris received valuable support from the Stroke Association but felt there was more to her situation, so returned to her GP.

'To my horror, she told me that she was there for my physical health not my mental health, and that in her opinion I didn't have a problem,' says Chris.

'I left the surgery in tears because I thought, if I can't get help here, then where do I go?'

As she was leaving, Chris saw a stand being set up by Alzheimer's Society, so spoke to a staff member.

'I was sent a leaflet about vascular dementia,' she says, 'and

as I read it I kept thinking, "That's me."'

In late 2016, Chris was diagnosed with young-onset vascular dementia at an elderly care assessment unit, having not long turned 60.

'That devastated me,' she says. 'I went home and cried for three months, because I thought I'd been given a death sentence.'

Chris later decided to contact Alzheimer's Society, where her call was answered by the same staff member she'd met at the GP surgery, who arranged to visit with a colleague.

'I had so many questions, but they were fantastic,' says Chris. 'It was a horrible diagnosis to receive but at least I now knew what I was dealing with.'

Chris attended the Society's Live Well with dementia programme, which she describes as a 'real lifesaver'.

However, she was beginning to struggle with living on her own, sometimes forgetting to eat proper meals. Heather suggested that Chris move from Cardiff to Eastbourne to live with her.

'I was absolutely gobsmacked, because I didn't know if Heather realised what she was taking on or how I might become,' says Chris.

'I couldn't believe that somebody loved me and cared for me enough that they would be prepared to look after me. I think it's a huge sacrifice.'

Legal authority

Although living with Heather has been positive, Chris continues to experience fatigue, difficulties in finding words, memory problems and anxiety.

‘Some days I just don’t want to talk, don’t want to go out and I just need some space to clear my head,’ she says.

‘But Heather gets it – she understands my dementia far better than anybody else.’

For this reason, Chris has set up two lasting power of attorneys, one for property and financial affairs, the other for health and welfare issues – to give Heather the legal authority to make decisions on her behalf if she needs her to.

‘It’s difficult for my family, being so far away, to know my needs, whereas Heather does know,’ she says.

Chris has experienced difficulties getting the right support from the benefits system.

Having retired due to ill health, her application for Employment and support allowance was refused. Although she lost an initial appeal, this was later overturned at a tribunal.

‘I wanted to challenge it because there are lots of people with dementia who wouldn’t be able to go through that process,’ she says.

‘It’s the same with the Personal independence payment. Why can’t the government say this person with dementia doesn’t need to be sent these complex forms every two or three years and go through the whole process all over again?’

Useful not useless

After deciding to get more involved in Alzheimer’s Society’s work, Chris joined a panel – now part of the Focus on Dementia Network – to have her say on local and national issues affecting people with dementia.

She has also given talks about her experiences, including one to members of the local Chinese community, and has sat on Society job interview panels.

‘By not working and not being able to do a lot of things I started to feel useless, but now I feel useful and better about myself,’ she says.

Chris is also contributing to an Alzheimer’s Society project to identify and address the specific

needs of LGBT+ (lesbian, gay, bisexual and trans) people who are affected by dementia.

‘A lot of people maybe wouldn’t feel free to tell people that they are LGBT+ or feel comfortable among those who they do tell,’ she says. ‘And they tend to not go to groups.’

‘I think it’s even more difficult for trans people to feel accepted as who they are. If they can know that Alzheimer’s Society is open and treats people fairly, then it may not be such an issue for them to approach the Society if they’ve got a diagnosis of dementia.’

‘There is still quite a lot of prejudice out there, but I think that if Alzheimer’s Society gets it right that will help everyone have a better understanding.’

Chris has certainly encountered situations that could have been better handled by the professionals involved.

‘If I go to a medical appointment and Heather’s with me, people should perhaps just ask who she is, rather than me having to explain that it’s my partner,’ she says.

‘Even then, sometimes you’re fronted with a stone-cold response and awkwardness.’

As well as dementia, Chris has been diagnosed with vascular Parkinsonism, where Parkinson’s-like symptoms are caused by restricted blood supply to the brain. She was also recently told that she might have Parkinson’s disease.

Despite all this, she remains determined to make a difference.

‘I’m well aware that my lifespan probably won’t be as long as it would be if I didn’t have these conditions,’ she says.

‘That’s why it’s important to do what I can while I still can.’





Next steps

- For our booklet LGBT: Living with dementia (1511) and factsheet Supporting a lesbian, gay, bisexual or trans person with dementia (480), see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- Use our online directory to find services near you – visit alzheimers.org.uk/dementiaconnect
- Young Dementia Network has produced a guide to help GPs recognise dementia in younger people – visit www.youngdementiauk.org/gp-guide

World of difference

A Belfast man with dementia has gained a new lease of life with the support of a Side by Side volunteer.

Our Side by Side service brings people with dementia together with like-minded volunteers so they can continue to enjoy their interests and passions.

Ian McKee in Belfast volunteered after reading about Side by Side in a local newspaper article.

'I'm one of these guys who have to give something back, you can't just take,' says Ian, who retired 12 years ago.

Raymond Scott, who has Alzheimer's, loves games and was connected to Ian through Side by Side. In their regular visits, Raymond has shown Ian how to play chess and dominoes.

'Having someone to play chess with is really important for me,' says Raymond.

'With playing chess, you're concentrating. I'm thinking, "What's his next move? What is he doing? What's his strategy?"'

There is one drawback, however.

'I've taught him too well,' jokes Raymond. 'I showed him all the sneaky moves I have and now he beats me!'

Improvement

Raymond's wife Maree recalls a time when he would arrive home in a panic after getting lost, or struggle to communicate. While he still has bad days as well as good, she says that Ian's company has made a major difference.

Maree contacted the Society when Raymond was diagnosed.

'At that time he couldn't have held a conversation with you – he wasn't good,' she says.

'I'm not into games, and he just needed more company and mental stimulation.

'There's been a big change, a marked improvement. It has made a world of difference.

'I couldn't have coped on my own the way he was before. Now we go places and do things.'

Peas in a pod

Teaming up with Raymond has also had a positive impact on Ian.

'I have a very good relationship with him, and vice versa – we bounce off each other,' he says.

'I'm not a Monday person, I hate Mondays, but we have a cup of coffee and put the world to rights.

'By the time I leave Raymond at a quarter to one, I feel really brilliant. I get a lot out of it, you've contributed something.'

David Moore, the Side by Side co-ordinator who brought Ian and Raymond together, says the men are like old friends.

'They banter with each other and I think it's that Belfast sense of humour that they both share,' he says.

'They are not afraid to take the mick out of each other, which shows how relaxed they are together – like two peas in a pod.'

Companionship

Although he had no personal connection to dementia before meeting Raymond, Ian has received ongoing training and support.

David says that as well as being reliable, volunteers need to have an open mind and a can-do attitude.

'Too many people are facing dementia alone,' he says, 'and something as simple as a few hours doing something you love can make an enormous difference in providing companionship, stimulation and enjoyment.'

Ian urges anyone who is considering becoming a volunteer to go for it.

'I get a lot out of it,' he says. 'Raymond has added to my life.'

The feeling is certainly mutual.

'Ian is full of banter which is great fun – we keep each other going,' says Raymond. 'I love to see him every week.'



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.



Let's chat

A Dementia Friends Champion in Coventry has produced reminiscence cards that draw on South Asian experiences and culture.

Taruna Chauhan is passionate about improving dementia care, and when she saw that reminiscence resources weren't relevant to many people who weren't brought up in the UK, she had to do something about it.

'I found there were no culturally-specific reminiscence cards for people of South Asian origin who had dementia,' says Taruna. 'The cards available were ideal for British-born people with dementia, but meaningless otherwise.'

Taruna is no stranger to taking the initiative – as a Dementia Friends Champion she holds information sessions to encourage others to make a difference for people living with dementia.

She drew on her own Hindu Indian background to create a set of cards called Let's Chat, and she hopes these would prompt memories for people from other South Asian communities too.

'The Let's Chat cards are themed by food, travel, clothes and religion,' says Taruna, 'and a deck of 25 means there's enough variety to have lots of conversation.'

Do something

Taruna, aged 54, lives in Coventry and was born in Kenya to Indian parents. Through her training and consultancy work, she helps care homes and home care agencies to make sure they are meeting Care Quality Commission standards.

She says, 'I became a Dementia Friends Champion to raise awareness of dementia in Asian communities. I realised that awareness was low, so I thought, "Let me do something about it in my area."'

Taruna used photos that her husband and friends had taken on one side of each Let's Chat card, with brief descriptions on the other side to prompt conversation. The pictures range from classic Bollywood posters and foods to brightly coloured floor patterns used when celebrating Diwali.

'The prompts on the back are also useful because a carer not from the South Asian community might not know what the photo is of.'

Taruna has had good feedback about the cards from care providers, and she hopes she can distribute them more widely in future.

'If my product can help even one person with dementia to be supported more effectively, then that is an achievement.'



To find out more about Taruna's Let's Chat cards, email taruna@tchauhanconsultancy.co.uk or call 07910 761122.

Try something new

See our catalogue



Our latest Daily living aids catalogue features a range of products to help with day-to-day life, from clocks and cutlery to games and activities. **If you didn't receive a catalogue with this magazine, call 0300 124 0900 (local rate) or visit shop.alzheimers.org.uk**

Become a Dementia Friends Champion



A Dementia Friends Champion is a volunteer who encourages others to make a positive difference to people living with dementia in their community.

They do this by providing information sessions about dementia, highlighting the personal impact of the condition and inspiring others to take action.

Dementia Friends Champions also receive support to help them in their volunteering role.

Visit dementiafriends.org.uk to find out more.

Spiritual connections

A team of Dementia Friends in Essex is enabling people affected by dementia to continue worshipping at regular church services.

Two years ago, a Methodist study day provided a turning point for Julie Peek's work with her local churches. She had recently taken up a new role – Mission Enabler for Older People – at the Highland and Wesley Methodist Churches in Leigh-on-Sea, Essex.

'My focus was drawn to the difficulties for people living with dementia in expressing and connecting with their own spirituality,' says Julie. 'I came away with the conviction that as churches we really need to be more flexible and do more.'

Since then, the support and input of an enthusiastic team of volunteers and the minister, Rev Julia Monaghan – all of them Dementia Friends – have transformed how they include and involve people affected by the condition.

Memory Worship

The first step was joining the local dementia action alliance, which covers the Southend-on-Sea area, and setting out an action plan.

Although local churches offered peer support, a day centre and a memory café for people affected by dementia, Julie was keen to make services of worship themselves dementia friendly.

'It felt logical and practical to combine the support of a memory café with the spirituality of a church service,' she says. 'This is how Memory Worship came to be.'

'This is a programme of monthly services designed around the Christian festivals, with a regular pattern of welcome, singing well-known hymns, reading familiar passages of scripture and saying the Lord's Prayer together. These are followed with themed activities that give everyone the opportunity to get involved and be creative.'

'Teamwork is very much the order of the day, as volunteers offer support with craft activities, musical accompaniment, hospitality, cake making and companionship. We have regular team training supported by Alzheimer's Society.'

Familiarity and fulfilment

Julie is conscious of the need for believers who practise a religion to be able to continue to worship, despite the challenges that dementia may bring to this. She emphasises the ways in which ritual and music can help.

'I now understand worship to be a channel for recalling the past, creating feelings of comfort, familiarity and spiritual fulfilment,' she says.

'Music is a very powerful trigger for memory recall and can take people back to a time when they felt safe and held by God.'

'Each month brings a new example of the power of music in action – a familiar hymn has the ability to awaken feelings of wellbeing and a memory for words without a hymn sheet.'



For more about our work with faith communities, see alzheimers.org.uk/faith or email programmepartnership@alzheimers.org.uk



A website that offers more

Rik Williams, in our Digital team, reports on how we're improving our website in partnership with people affected by dementia.

When Alzheimer's Society launched a new brand last year, we made our redesigned website as helpful as we could. But even bigger developments have been taking place since then, and people affected by dementia have played a vital role in this.

In April, we changed the technology that powers our website, making it easier for you to find information, advice, real-life stories and support.

Although the site might not look very different, you have more control over the kinds of information you see, with links to related content below each article that you can filter by type.

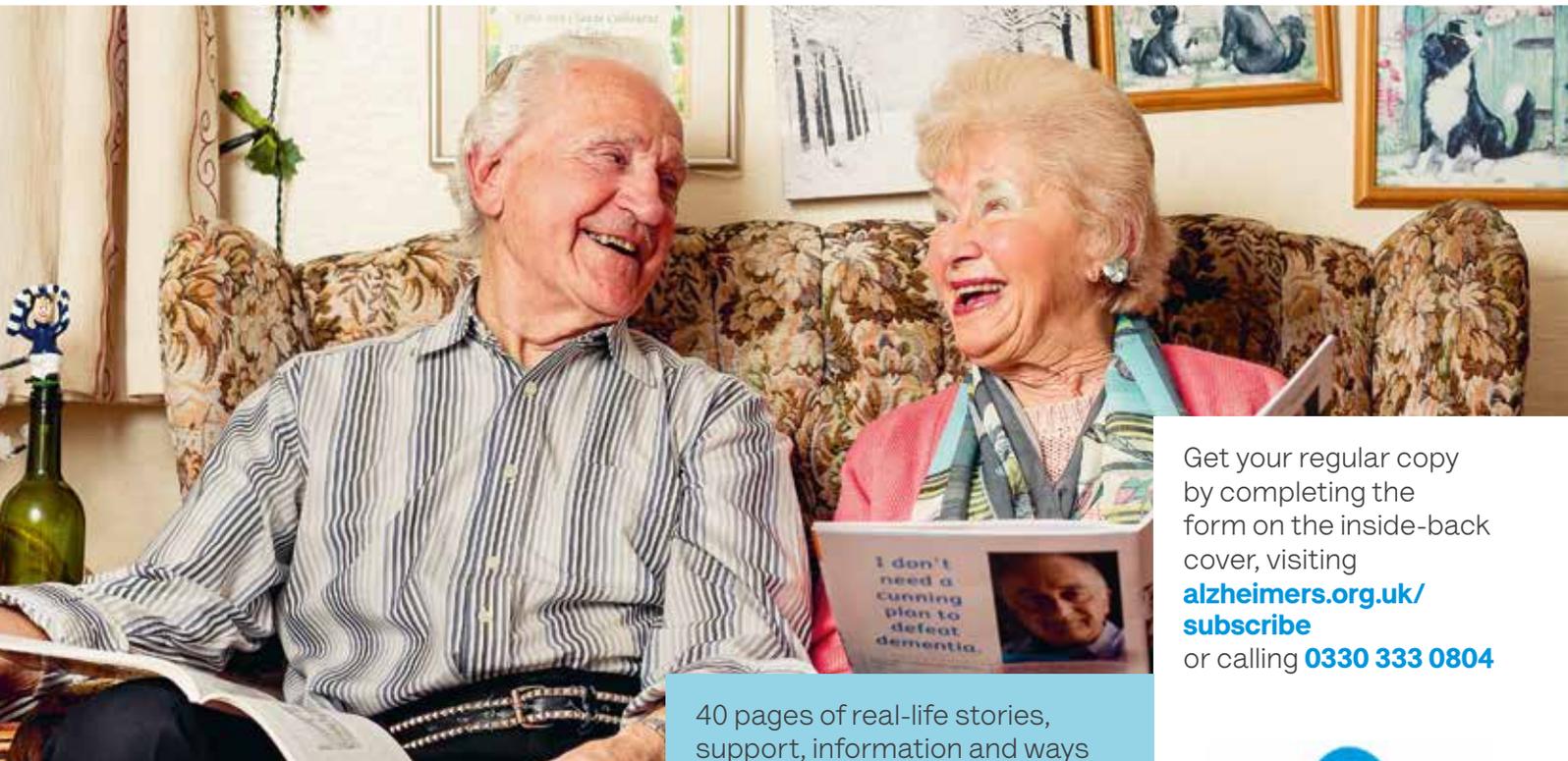
We've made it easier to find dementia support in your area and to share information about specific services with other people. Searching for information on the website also works better, and our online forms are simpler to use.

This is only the beginning – the new technology behind our website makes it quicker and less complicated for us to keep making improvements.

None of this would be possible without the people with dementia and carers who have been testing new features for us. Combined with online feedback and other research we've done into people's needs, this all helps to make sure you can use our website to get the right support at the right time.

We believe that no website is ever truly 'finished', and we're excited about the further changes we'll be able to make to continue improving ours.

Visit alzheimers.org.uk for information, advice, stories and much more.



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

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

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

**Subscribe to
Dementia together
magazine today**





Llandudno success

Llandudno Hospital has become the first hospital in North Wales to be recognised as working to become dementia friendly by Alzheimer's Society.

The hospital has dementia support workers who provide additional care, companionship and activities for patients who have dementia.

Staff have also met with local businesses, schools and community health facilities, like pharmacies and dentists, to raise awareness about how to support people with dementia. Over 200 people have become Dementia Friends through the hospital.

Tina Macphail-Owen, Matron for Llandudno Hospital, said, 'Everyone has really bought into the vision of improving life for people with dementia, not just in our hospital but in Llandudno and the wider Conwy community as well.'

Dementia-friendly London

London is stepping up its plans to become the world's first dementia-friendly capital city.

Mayor Sadiq Khan and representatives from major organisations such as Transport for London and the capital's emergency services underlined their commitment at the recent Dementia Friendly London Summit, held during Dementia Action Week.

As well as meeting people affected by dementia, attendees pledged to take actions towards creating a Dementia Friendly London.

Sadiq Khan said, 'There's so much we can all do to help people affected by dementia live well. At City Hall, I'm giving all staff the chance to become Dementia Friends and all our front-of-house staff are dementia aware. Transport for London is also making improvements for people with hidden disabilities.'

'I'm committed to working with Alzheimer's Society to make London the world's first dementia-friendly capital city.'

Find out more at alzheimers.org.uk/dementiafriendlylondon



Powerful discussion

People living with dementia in Northern Ireland have been sharing their experiences at a special listening event hosted by Alzheimer's Society at Malone House in Belfast.

Attendees spoke about seeking information, quality care and support in their homes, and challenges in funding care, all of which has a huge impact on their lives. The event received support from across the political spectrum. Michelle McIlveen, a Member of the Northern Ireland Assembly described it as a 'powerful discussion'.

The stories and experiences shared form part of Alzheimer's Society's new report, *Dementia – the true cost*, which calls for the social care system to be reformed.



Picture this

An art competition in west Kent has been helping children learn more about dementia. School pupils aged between four and 13 in Tonbridge were invited to create a picture on the theme of living well with the condition.

The winning entries, chosen by local people affected by dementia, were announced during Dementia Action Week and presented with a cash prize by the town's mayor. The best 12 entries will also be used in the 2019 calendar from Tonbridge Dementia Friendly Community, who organised the competition.

Chris Parker, the organisation's Chair, said, 'This is a way to engage with children who are likely to experience dementia at some time in their life – indeed they are the next generation of dementia carers. I believe art is an excellent way to reach out to children.'

One of the judges commented, 'It is evident that the children have a good understanding of dementia – they are intelligent pictures.'



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Strain on the family

After her mother developed dementia in her late 40s, Louise Thomson had to care for her while also raising a young family. Gareth Bracken meets a daughter shocked by what she has seen.

When Louise Thomson moved her young family from Essex to Surrey, she assumed that her mum Teresa, who lived nearby, would be on hand to offer support with childcare.

But those plans, and many other hopes for a settled family life, have been turned upside down by Teresa's dementia – a rare form called posterior cortical atrophy (PCA). Its progression has been dramatic, and Louise is not only raising two children without her mother's support but also caring for Teresa herself.

Peaceful and bubbly

Teresa, 56, was a bodybuilder who had owned a gym business and worked as a surgical nurse. Art was her great passion, particularly painting with acrylics.

'She was kind, peaceful and bubbly,' says Louise, who lives in Redhill with her partner Mark and children Oliver, 10, and Miley, 4.

'She became a vegetarian because she didn't want to hurt animals.'

It was around seven years ago, when Teresa was just 49, that Louise first noticed changes in her mum's behaviour.

Teresa started letting herself into Louise's house on her own, which she had never done previously.

She would also send very short replies to lengthy text messages, or even respond with a call, which again was unusual.

There were further problems a couple of years later when Teresa was looking after Oliver. This included Teresa forgetting to give him the lunch Louise had provided.

'He'd come home hungry and I'd notice his lunch box was still full,' says Louise, 32.

'Other times, Mum would forget that she was supposed to be having him.'

A doctor suggested that Teresa may have a thyroid problem, but tests came back clear, while they also mentioned 'brain fog' caused by the menopause.

Louise kept asking Teresa if she was OK, but her mum insisted it was just the menopause.

Teresa's partner Michael also told Louise not to worry.

'The more I pressed, the more angry and upset Mum got,' says Louise. 'I felt I was being this awful, naggy person.'

'After Mum lost her job, the occupational therapist said she had anxiety and depression, so I just ran with that.'

Turning point

As Teresa's only child, Louise was already feeling the pressure of responsibility when, in 2016, she arrived at Teresa's house to take her out for a pamper day.

'I got there and found her walking around the house naked,' says Louise. 'She was acting like there was nothing wrong.'

'We went to the doctor's and Mum was crying and saying, "I know I'm going to die."'

Teresa failed a series of neurological tests and couldn't

Quick read

Louise Thomson has been shocked by the devastating effects of posterior cortical atrophy (PCA) on her mum Teresa.

Having given up her job, Louise found herself supporting her mother, now 58, while also raising two young children.

Teresa's behaviour has sometimes been very challenging, including chasing Louise while shouting and swearing at her.

Louise believes there needs to be more awareness of PCA and hopes her story will show others that they aren't alone.

even recognise Louise. A brain scan at hospital in June 2016 then revealed that she had PCA, caused by Alzheimer's disease.

It was later suggested that Teresa had experienced a transient ischaemic attack – also known as a mini-stroke – a couple of months previously, which had quickened the onset of her dementia.

Michael gave up work immediately to become Teresa's main carer, while the family employed carers to support Teresa four times a day.

Teresa's behaviour could be challenging, such as chasing Louise around the house, swearing and screaming at her. Teresa has also experienced hallucinations.

'It's been hell,' says Louise. 'There have been so many occasions where I can't talk afterwards because I can't believe what just happened.'

Family pressures

Although it became clear that Teresa's needs would be better met in a care home, it was a struggle to find an appropriate place that would accept her.

Following another stroke and a four-month spell in hospital, Teresa entered what Louise describes as an 'amazing' home last September.

However, Teresa has since had seizures that have reduced her quality of life.

'She can't hold her own head up, and her arms and hands are fused in a particular position. She's out of bed for two hours a day,' says Louise.

'Every time she has a seizure it takes something away.

'There is sometimes a glimmer of who she used to be, like this certain movement she does with her shoulders, but it's less and less now.'

The time and energy needed to support her mum led to Louise giving up her job as a childminder while continuing to raise a young family.

'I was always doing admin work – forms, assessments, appointments,' she says.

'It was a real strain on home life, really bad. I had a meltdown and was put on antidepressants.'

Her son Oliver has also been affected by Teresa's illness.

'They had a close relationship, so he's been down about it,' says Louise.

'He says he misses his nanny but that he doesn't want to see her because she looks "dead".'

Louise has received strong support from friends, family and the church where Mark works as a caretaker, as well as other members of a PCA group on Facebook.

'I would work as a team with Michael on the admin, and had friends or family who could help

look after the children,' she says. 'I'm also really lucky that Mark is so good – we've been through a lot together.'

Not alone

Louise is frank about the emotional toll that her mum's dementia has had on her.

'I got really angry a few times,' she says. 'I've been through cervical cancer and miscarriages, then finally got pregnant and moved here to be closer to Mum, and this happened. It pissed me off.'

'I've also got upset, thinking that one day this will be me, which is selfish really. But I've turned down genetic tests – I don't want to know.'

Louise feels able to be so open about her experiences because Teresa has become so far removed from who she once was.

'I don't feel like it's my Mum anymore, to me they aren't the same person,' she says. 'It's such a shock to go from one to the other.'

Louise hopes that sharing her experiences will help raise awareness of PCA and the challenges it brings. This includes how different its initial symptoms, such as problems with vision, can be.

'Dementia isn't just a forgetful old person – I was so shocked by some of the PCA symptoms,' she says. 'I hope people might read my story and think, "I'm not alone."'



Posterior cortical atrophy

Posterior cortical atrophy (PCA), also known as Benson's syndrome, is a rarer form of dementia.

In PCA, damage to the rear of the brain – usually caused by Alzheimer's disease – can make it harder for the person to process what they see and where things are in relation to each other.

Early symptoms may include problems with identifying objects, reading or judging distances when going downstairs.



Photographs: Lee Shaughnessy

Next steps

- For our Rarer causes of dementia (442) factsheet, go to alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- Use our online directory to find services near you – visit alzheimers.org.uk/dementiaconnect
- For PCA-specific support group meetings, information and advice, see www.raredementiasupport.org/pca

Smarter policing



Quick read

A project in Cumbria is helping to reduce unnecessary police call-outs involving people with dementia.

Dignity in Dementia works with families to identify and address the reasons behind their relative with dementia behaving in a certain way.

For example, Linda Mason has found a way to prevent her mum Cecily, who has dementia, mistakenly reporting stolen property to the police.

The project has also trained officers who are called out in how best to communicate with a person with dementia.

Calling police to an incident involving a person with dementia can be needlessly stressful if a crime hasn't been committed. Gareth Bracken explores a project reducing unnecessary call-outs.

If a person with dementia has gone missing or is in a state of confusion or distress, the police might be called even if no crime has taken place. Even with the best intentions, this could sometimes make the situation worse.

To address this, a social enterprise called Dignity in Dementia launched a project in Cumbria to reduce and prevent such call-outs. It has also trained police officers in how best to handle situations when they are called out.

Stressful

'A family carer told us about her experience when her mother had gone missing,' says Lesley Gill, co-founder of Dignity in Dementia. 'It wasn't especially positive, as the police inadvertently made the situation more stressful for them both.'

'A community sergeant then told us that police officers didn't have much knowledge of dementia and could indeed sometimes make situations more complicated and protracted.'

Dignity in Dementia started running training sessions at police stations across Cumbria to help officers, as well as command and control room staff, better understand dementia and how to communicate with someone who has the condition.

This included advice on how to search for a missing person.

'We explained that it is better not to shout their name in a frantic manner, as this is likely to confuse and scare them more,' says Lesley. 'Say their name loudly but in a really friendly way, and ask for their help with something they enjoy or know about.'

Cumbria's Police and Crime Commissioner, Peter McCall, attended one of the sessions.

'It offered some really practical guidance to enable frontline staff to deal more effectively with people with dementia in crisis,' he says.

Inspector Mike James, who has worked closely with the Dignity in Dementia team, thought the training was excellent.

'Officers with many years' service were describing it as the best input they'd ever had,' he says.

Successful strategies

Officers called out to a person with dementia could also offer the family a referral to Dignity in Dementia.

Dignity in Dementia would visit and look into the person's history to see what could be triggering the behaviour that led to the police involvement. They would also suggest how to reduce or prevent it.

Linda Mason's mum, Cecily, was diagnosed with vascular dementia in 2012.

Cecily lives alone and, as her dementia progressed, would mistakenly accuse visiting family members or care staff of stealing from her. On one occasion she called the police to report a missing bank card, which led to a visit from an officer.

'Thankfully he was very understanding and kind – he certainly appeared to understand about dementia,' says Linda.

At the suggestion of Dignity in Dementia, the family placed a whiteboard in Cecily's bungalow that reads, 'Mum don't worry about your bank card, I've got it and will bring it back with me when I visit later, love Linda.'

'It worked,' says Linda. 'Mum doesn't ask about her bank card anymore and hasn't phoned the police again.'

'We also understand much more about why she may behave in a certain way when she is

anxious, unsure or upset. We try really hard to keep her on an even keel and work hard at trying to be more patient.'

Positive relationships

Another person supported by the project is Flo Jamieson, 86, who was diagnosed with Alzheimer's in 2013. Having gone looking for her childhood home, she was found by a member of the public, who phoned the police.

Flo's daughter-in-law Christine is full of praise for the attending officer who waited with Flo until the family arrived.

'She was wonderful and seemed to understand dementia really well, building up a positive relationship with Flo,' says Christine.

A visit from Dignity in Dementia again proved valuable.

'Lesley asked lots of questions about Flo to build up a picture of her life,' says Christine.

'As a family we had already discussed different ways to prevent Flo from wandering off again, so I was able to share our thoughts with Lesley and gain advice.'

'We have now tried new things to encourage Flo to feel that she is still needed around the house, as we believe that if she feels

useful then she's less likely to feel the need to make her way back to her childhood home.'

Achieving change

The project has led to a reduction in police call-outs, while those who do attend are now much more prepared.

'Officers are better equipped to deal with situations involving people with dementia and avoid them escalating,' says Peter.

Mike has also noted additional benefits for colleagues.

'Sometimes it's difficult for police officers to walk away and simply stop thinking about a person's situation, so it helps to know that someone else is going to carry on the work,' he says.

The project has clearly bought about positive change for all involved.

As Christine concludes, 'The GP will prescribe drugs, the mental health team will assess the person and there are some good local activity groups to stimulate people with dementia.'

'However, actually having Dignity in Dementia, who understand and can help and advise us with the daily struggle of caring for someone with dementia, is priceless.'

Next steps

- Read our **Changes in behaviour (525) factsheet** at alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- For more information about Dignity in Dementia and related resources, visit www.dignityindementia.org
- For our dementia awareness training for emergency services staff, email dementiatraining@alzheimers.org.uk or call 01904 567909.



Little visitors

Spending quality time with young children can be a big boost for people with dementia. **Gareth Bracken** reports on a scheme that's keeping communities connected.

An otherwise ordinary afternoon at Stradbroke Court care home in Lowestoft, Suffolk has been immediately brightened by a collection of young visitors.

The babies and toddlers are here with their parents to spend time with residents, many of whom have dementia.

It's all part of Little Visitors, an intergenerational scheme across Norfolk and Suffolk run by the social enterprise Friend in Deed.

'I've always been passionate about helping older people live well,' says Kelly Lindsay, the founder of Friend in Deed.

'My nan had Alzheimer's and went into a good care home, but there wasn't enough interaction.

'We need to reach out to older people with dementia and offer as many things as we can.

'When I was a teacher I also noticed that some younger people aren't given opportunities to understand how to be kind and empathetic to others.'

Back in time

The children and residents are soon at ease with each other – playing games, chatting or simply interacting.

'We love the children coming here,' says Maisie, one of the residents. 'They're absolutely gorgeous, they really are lovely.

'It's very nice to see them, we like to include them in things. It makes the day really.

'I want to take them home!'

Having been playing a card game with some of the residents, three-year old Alfie now turns his attention to decorating the walking frame of Dilys, using their initials.

'He's very clever,' says an impressed Dilys, who is also enjoying the company of Alfie's younger sister, nine-month old Matilda.

'She's a happy little girl – it's lovely to see a little child content,' she says.

'I like to see children with good manners, well-behaved. The children today have all been very good.'

Another resident, Maggie, thinks the session is brilliant.

'We love it as much as they do,' she says.

'It's maybe because it's a step back in time, it makes us feel a lot younger.

'We see them come through and we want to play with them – and we do!'

Community feel

The Little Visitors scheme creates a sense of wellbeing among residents, according to Stradbroke Court manager Dawn Bunter.

'Living in a care home can be very restrictive and people can feel ostracised, so it's important that a person with dementia gets to see people from the outside world in a happy environment,' she says.

Quick read

Babies and toddlers have been visiting residents with dementia at Stradbroke Court care home in Lowestoft, Suffolk.

The Little Visitors scheme, run by social enterprise Friend in Deed, sees them play games, chat and generally interact.

Maisie says the residents love the children's visits, and that seeing them makes her day.

Another resident, Maggie, says it's a step back in time that makes her feel a lot younger.

'Being around children and other families gives that feeling of community.

'Some residents won't respond to us but when the children are here they want to join in.'

The visiting youngsters, such as 13-month old Erin, also benefit from spending time with new faces.

'It's really nice to see her interacting with people of all ages, not just other children or her parents,' says mum Alice. 'It helps her people skills too.'

Also meeting residents today is 12-month old Erica and her mum Maria.

'We always see the difference it makes to them and to Erica,' says Maria, who has now noticed her daughter become gentler with the family dog back home.



Building bonds

As a regular visitor to the home, Alfie has built up a good relationship with residents, which pleases his mum Kelly.

'Alfie is normally really shy and doesn't talk to anyone, but he'll talk and interact here,' she says.

'We haven't got any older relatives so it's nice for him to learn to interact with older people.'

One of the strongest bonds to have developed is between Alfie and resident Graham.

Graham doesn't have dementia but is still very much involved in the project, much to Alfie's delight.

'He loves Graham and talks about him all the time at home – he was excited to see him today,' says Kelly.

Graham, who has been playing card games and skittles with Alfie, never had any children of his own.

'This is a new type of thing to me, it's a bit of fun,' he says.

He is soon interrupted by an excited Alfie, who has found more cards for them to match up.

'Oh look at this, here we go!' says Graham, as the two start playing again.

Alfie later takes a break from his busy schedule to explain why he enjoys visiting the home so much.

'I like playing with Graham,' he says. 'We got matching penguin pairs!'

With that he scampers off, having spotted another game on the other side of the room.

Promoting kindness

Dawn feels the project is helping to break down the stigma that can surround residential care.

'People see care homes as places not to visit or be around, but this educates children that people shouldn't be shied away from,' she says.

Kelly, who is also a Dementia Friends Champion, is now seeking further care homes and volunteers to help expand Little Visitors into new areas in the east of England.

'I'm proud of the positive impact we're having on people living with dementia,' she says.

'We need to promote kindness and that we should look after people, regardless of who they are or how we know them.'

Next steps

- Visit dementiafriends.org.uk to become a Dementia Friend or Dementia Friends Champion.
- Find resources for schools and young people at alzheimers.org.uk/schools
- For our Keeping active and involved (1506) booklet, go to alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

One reader with dementia writes about the power of smiling, while another shares the impact of her mother's use of dolls.

New purpose

I have lived with type 1 diabetes and epilepsy for a long time, and a few years ago I was diagnosed with Alzheimer's disease, which also has its challenges.

My long-suffering husband and my son, who is now in his 30s and lives in London, are both patient with me, especially with my constant repetitions. I have a few friends who are kind and chatty, which is lovely.

Once a week my husband and I join a small group of people in a local pub. We laugh, drink and eat, and discuss an important topic that one of us has thought of. I enjoy these evenings but sometimes I can suddenly feel too drained to continue, so I tell them that I have to go home and they accept this.

I have also found that most people are usually willing to help. Sometimes when I am out, I get lost or stuck, I can't move or remember where I'm going. I ask everyone for help. Kind strangers have pointed me in the right direction or brought me home. People love to help, and have told me that it makes them feel useful.

I have found a new purpose in life: I try to smile warmly and personally at everyone I pass in the streets where I walk. Some people responded straight away, others only after a few weeks. Now I have a network of local people I recognise and who call out or wave to me as I go past.

Teresa Brett, Cambridgeshire

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

Ubuntu and life history

My father was diagnosed with Alzheimer's in 2013 and so our whole family immersed ourselves in finding out as much about it as possible and how to live well with the condition. We enjoyed Singing for the Brain and the dementia cafés very much, and I miss them still now that Dad is no longer with us.

I'm not sure if it was a Northern thing or just a Dad thing, but we weren't a very touchy-feely family. I found it hard to put into words what I felt for Dad and wished I'd heard about the concept of Ubuntu from a South African friend, Hazel, when I was trying to convey my thoughts and feelings during the making of his life history book.

Ubuntu comes from the Xhosa/Zulu culture and community into which Nelson Mandela and Desmond Tutu were born, and can be summarised in the phrase, 'A person is a person because of other people.' How true that is! Our community of loved ones, friends and family have shaped us all, just as who we have been or are for them will have shaped their lives too.

Why not, as well as putting facts, memories, events and photos of the person with dementia in a life history book, you could try to make a record of what they have meant or mean to you now, for them and you to reflect on. This could encourage conversations about their lives too, and what makes them unique.

Christine Trotter, County Durham

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 August/September issue to arrive by 9 July. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

Doll use

I wanted to write in to highlight the use of dolls for people with dementia, particularly for those in the advanced stages. It can sometimes be hard to find activities that are appropriate for people who might have lost a lot of their previous abilities, and I believe that doll use can make all the difference.

My mum is now unable to walk following a fall nearly two years ago and so activities she previously enjoyed, such as attending a day centre, walking and baking, are no longer an option. She now has a collection of dolls and these bring so much joy to her life.

She spends hours talking away to them, cuddling them and even sometimes trying to feed them. Indeed, some of her most lucid (and happy) moments are when she is interacting with one of these dolls. They also have a calming effect and bring out that nurturing instinct, which I believe never leaves a person. As well as being therapeutic for my mum, it also gives us pleasure as family members, to see her so contented and happy.

I just wanted to highlight this to other readers as it is something that can enrich the lives of a person with dementia. While the use of dolls might not be appropriate or suitable for everyone, I urge people to give it a try and see what happens.

Michelle Loos, London

Society response

It's wonderful to hear that your mum is benefitting from doll use as her dementia progresses. It's so important to find activities that are meaningful for the particular individual, since everyone is different.

Some people are cautious about using dolls and soft toys in this way, as care staff still need to understand and respect the person rather than seeing or treating them as a child. Of course, whether and when to use a doll should be the person's choice – leaving it within reach means they could pick it up if they want it.

It's easy to make assumptions about who'd want to use a doll or soft toy – a man may want to, while it might be distressing for a woman who's had a miscarriage or children taken into care.

We'd suggest using a doll with a soft body that doesn't make noises and which has eyes that open and close. Refer to it in the same way the person does – don't call it their 'baby' unless they do.

As you say, it's not suitable for everyone. It underlines the importance of understanding the person and their life experiences, and putting them at the centre of decisions about their care.

Could you help someone with dementia do the things they love?

Volunteer for our **Side by Side** service to share your passion with someone with dementia.

'The other week we went up to my other best place [which] is the garden centre. I love that. I love gardens and I love centres where you can wander around and have a cup of tea and a look'.

Side by Side Service User

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

Get in touch

0300 222 5706

**volunteers@
alzheimers.org.uk**





Jules Emberton
Portsmouth, aged 54
with frontotemporal
dementia

What's changed most since your diagnosis?

I get more frustrated now when people aren't being understanding. Having frontotemporal dementia, your behaviour changes anyway, and if my back's up about it I can get on my soapbox. My attitude's changed and everybody else needs to catch up!

What would you take to your desert island?

I'd take my memory box. I made it after my son bought me a Talking photo album from the Society's online shop. A colleague lost her husband three years ago and had just got around to doing a memory box, but I wanted to make mine while I'm alive. The photos and objects in it help trigger memories.

How has Alzheimer's Society helped you?

I got a huge list of Alzheimer's Society publications – all factual, not like anything you'd get by googling. I work in a carpet store, and I'm also getting the Society's help to make the company more dementia friendly.

What song or tune sums up your life so far?

What a wonderful world, by Louis Armstrong. It's my favourite song – while it's quite slow, it's very uplifting.

What is your most treasured possession?

I haven't got any material things that I treasure, but I would say my children and grandchildren. I see them every day on FaceTime video calls – they keep me going.

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.

Ma is very much her usual self. Her self-imposed purpose in the house is to iron everything that moves, which she loves. At 92, she has common health difficulties with her vision and feet, but she has an optician's appointment and is having special shoes made. We hope she likes them, as her strong views often prevail – 'I can't be doing with them!'

There is a certain sadness in her conversation, mainly about longing for her old bungalow and more independent life, plus objections about the 'concrete garden' at her son's house and the 'indescribably dull' neighbours: 'They're all elderly!' Her current complaint about where she is living is that it is 'not my choice of residence.'

One real challenge is encouraging her to get out and about more. She gets lonely when the house is empty and people are busy elsewhere. She has a great opportunity to join the local Good Neighbours project, which supports older people through a buddy, but she is reluctant and they need her willingness.

I have also given the family details of Alzheimer's Society's local Side by Side volunteers, who help people with dementia to continue enjoying the things they love doing, but again she needs to want to be part of it. 'I don't want to go gardening in other people's gardens!'

When she was living with us, we just used to say, 'Get your coat on, we're going out!' and she would go on to enjoy the outing.

Dilly, a daughter-in-law

(continued next issue)



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



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

‘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.’

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People at a south London dementia café look at new women's fashions designed for easier dressing.

New womenswear

Primrose Café had just moved to a new venue in Bermondsey, south London, when we visited with some specially designed women's clothes for them to try out. The clothes were from the Able Label's latest range, many of which are available in our online shop – see shop.alzheimers.org.uk

As people with dementia and carers arrived to catch up with each other's highs and lows, Katie Ellis was on hand to show them how the Able Label's clothes could make dressing and undressing easier.

Katie founded the Able Label after seeing how Parkinson's disease dementia affected her gran's ability to dress herself, and the impact this had on her gran's independence and sense of self. She was determined that women with similar conditions should be able to dress themselves in the clothes they like for as long as possible.

Attractive

While they are designed to be attractive, none of the Able Label's clothes have buttons or other fiddly fastenings, using strong velcro pads instead.

At Primrose Café, Bernie told Katie how her mother is finding it difficult to work zips, and so velcro could be helpful.

'Our clothes have the option of opening at the front,' added Katie, 'so you don't need to put them on over your head. The stretchy fabric on our jersey styles mean that putting your arms into the armholes is easier too.'

Although Caroline wondered if the buttons on one top – which are decorative only – might confuse people, Katie said, 'We've found that people find the buttons helpful because they can tell exactly where each velcro pad is.'

Bernie appreciated the importance of supporting a person with dementia to remain as independent as possible.

'I try to keep my mother doing stuff for herself – use it or lose it!' said Bernie. 'I don't want to do things for her automatically, until she actually needs it.'

Easywear

As Jean admired a soft pink 'Camilla' shirt, her daughters, Linda and Jan, recognised the fabric as seersucker.

'You used to wear seersucker, Mum!' said Linda. Seeing how simply the velcro pads could be done up at the front, she added, 'That would be much easier for you.'

Jean also liked the 'Charlie' woven floral shirt, saying, 'It's pretty!'

Katie pointed out that the tops were cut in a way so they would still look great and feel comfortable if someone spends a lot of time sitting down.

Showing them a pair of black 'Frankie' trousers, Katie said, 'Our trousers are jersey, and you just pull them up, with no fastening at the waist.'

Feeling the material, Linda said, 'They're similar to what you wear, Mum, but softer. And you just pull them on, not like when you wear your jeans.'

Linda also appreciated the fact that sizes were defined clearly.



Quality

Although clothes from the Able Label aren't the cheapest available – £45 for a cape and £47.50 for a seersucker shirt or a pair of jersey trousers – they are VAT exempt if bought for a person with dementia, which means almost a fifth off the price.

Katie noted that the prices compare well to clothes of a similar quality, and Bernie – a machinist – appreciated how much time would go into sewing the velcro pads on securely. The premium velcro used also means that the pads will last, though Katie advised keeping them closed while washing them to help this.

Popular

Katie also brought popular items that have been available in our online shop for some time. These included a 'Debbie' wrap skirt, which can be put on without bending, and 'Lilly' knitted cape, which is one of their best sellers.

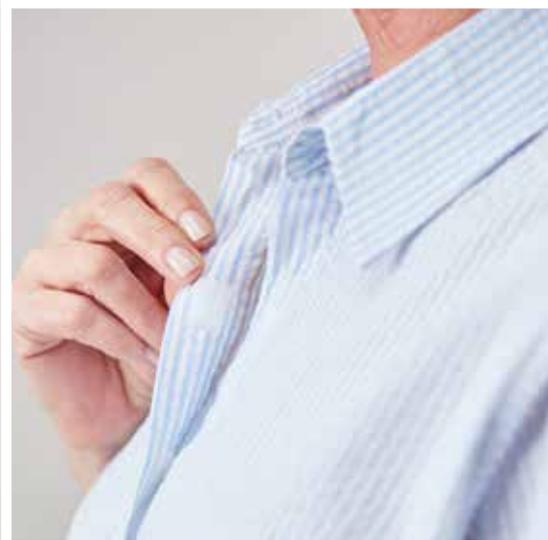
Seeing how soft the cape was, Deniz said, 'I like that, I'd buy it as a present.' Then, gesturing to her daughter, she grinned and added, 'But I'd have to ask the boss!'

A number of people enjoyed feeling the fleece-lined 'Anna' non-slip bed socks, which come in a gift box.

'Ooh that is very nice, really nice and soft,' said Jean. 'I'll have a pair of them.'

Linda added, 'You wouldn't have to put slippers on, Mum!'

For a wide range of clothes from the Able Label, and many other useful products, see shop.alzheimers.org.uk or call 0300 124 0900 (local rate).



Win

See p39 for a chance to win a shirt, wrap top or socks from the Able Label.



Menswear?

We haven't been able to identify a similar range of easywear clothes for men. If you know of any, please let us know by emailing trading@alzheimers.org.uk



‘My husband, who has dementia, is making inappropriate sexual comments to care home staff, and I’m worried it may get worse. How do I balance his needs with other people’s?’

Inappropriate sexual behaviour

The diseases that cause dementia can damage parts of the brain that usually stop us behaving in inappropriate ways. Remarks or actions of a sexual nature can cause problems, particularly if directed at a friend or family member. However, it is important to realise that they are usually a symptom of the person’s dementia. Care home staff should know this and be trained in how to respond.

If someone with dementia is behaving in this way, they may not recognise the person or might mistake them for someone else. They may not be able to recall what people should or shouldn’t do or say in various contexts – for example, not to make sexually explicit remarks to a relative stranger.

Communication and understanding

Understanding that someone’s inappropriate sexual behaviour is probably caused by damage to their brain may help to make it easier to deal with. However, some friends or relatives may still find the behaviour difficult to deal with despite knowing this, and this could limit how they spend time with them.

Sometimes what we think of as sexual behaviour could actually be a person’s way of expressing discomfort, anxiety or distress. For example, they may take off their clothes in public simply because they are too hot, and so addressing the root cause should help.

If the person’s behaviour is intended to be sexual in nature, then you might be able to find a sensitive way to explain to them – calmly and without judgement – why it is inappropriate. This could take several attempts, and is likely to be less effective as the condition progresses.

Environment and behaviour

Our emotional need for physical intimacy doesn’t disappear just because we develop dementia. In some cases, it might be helpful for the person with dementia to express their sexuality by having some time alone with their partner, when they can both enjoy the comfort, pleasure and reassurance that this brings.

Inappropriate behaviour can also be a result of under-stimulation and boredom, so it might help to fill the day with engaging social activities – exercise, eating and drinking, doing housework, arts and crafts, or simply talking with other people.

Lastly, although drugs have been used to address sexually inappropriate behaviour, there isn’t good evidence that they work. Taking more medications increases the risk of side effects, and some drugs could make it harder for a person to communicate discomfort or distress. Drugs should only ever be considered if the behaviour is very serious, and only as a last resort once all other options have been tried.

Inappropriate sexual behaviour is often associated with behavioural variant frontotemporal dementia, because of damage to particular parts of the brain. However, it can be experienced with other types of dementia too. For more about the brain and dementia, see alzheimers.org.uk/braintour





Other members of our online community can understand what you're dealing with, even when family members might not.

Family problems

When you are caring for someone with dementia, having the practical and emotional support of family members can be enormously helpful. Of course, family relationships can be complicated – it's not unusual for problems to come up.

These could include some family members not pulling their weight, or avoiding situations because they aren't sure how to cope. They might give unwanted advice, and they may think they're being helpful when in reality they're making things more difficult.

Dealing with it

It's often tough to know how to bring these problems up, especially if they're connected to long-running issues between family members. Some people feel obliged to not say anything at all.

It can feel like you're on your own dealing with this and that there's nobody you can turn to who will understand.

On Talking Point, our online community, you will find a safe place where you can share these problems with other people who are able to relate to what you're going through.

Anonymity OK

When you join Talking Point, you can choose a username and picture that doesn't identify you. This means you can be as anonymous as you like, which might feel odd at first – most of us are used to other people knowing who we are.

However, anonymity is nothing unusual in this kind of online community. Some people use their real names, but it's perfectly OK to be one of the many members who choose a made-up name instead.

Special forum

You don't need to be a member of Talking Point to read most of the discussions that take place, which is great because you can have a good look around before deciding to sign up.

But there's also a section called the 'dealing with difficult feelings' forum, and this can only be seen by other community members. This makes it a particularly safe place to discuss family problems.

Whatever situation you are in, having a place where you can talk to others who are facing similar challenges, ask for suggestions and share experiences can help you feel less alone and better able to find solutions.



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

Readers tell us what they thought of this memoir and tribute from a son to his father.

The Songamminute Man

When Simon McDermott first used YouTube to share a 'carpool karaoke' session with his dad singing as they drove around Blackburn, no one could have predicted the response.

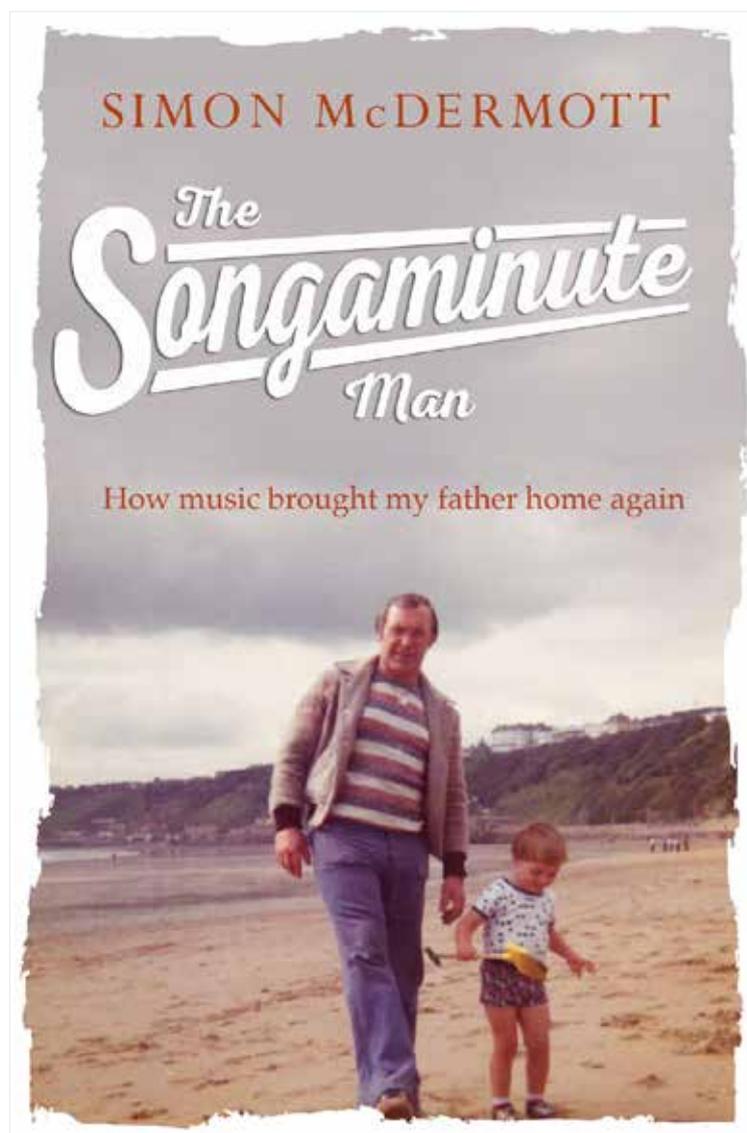
With so many people watching videos of each new song that he uploaded, Simon used the widespread media attention to raise dementia awareness and funds – over £150,000 for the Society – while also giving his dad the priceless experience of recording and releasing his own records.

Perhaps a book deal was inevitable after all this exposure, but there's a lot more to this account than might be expected.

Caroline Goodman-Ancell, in our Dementia Knowledge Centre, says, 'This is a compelling biography of Ted McDermott, also known as Teddy Mac or the Songamminute Man, who became a social media sensation at the "tender" age of 80, having been diagnosed with Alzheimer's in 2013.

'Told through the eyes of his son, friends and family, the reader is taken on a fascinating journey of Ted's life, from birth to present day.'

Pat Norris, who cares for her mother in Greater Manchester, says, 'Having watched the YouTube clips of the Songamminute Man, I mistakenly believed that the book of the same name would be an amusing tale of camaraderie between father and



son dealing with the effects of dementia by enjoying "karaoke" trips out in the car.

'It was, in fact, an emotionally "hard" read – an honest, sometimes painful, insight into the distress that can be caused when living with this condition.'

Explanatory

Gloria Potter, a carer in Kent, found it easy to identify with Simon's perspective.

She says, 'It was so explanatory of how things are with dementia – it read as though it was me writing the story. The book must have

been so hard to put into words and explain, because unless you are in that position, people just cannot imagine what it is like.

'I'm sure many carers looking after a loved one would love to read it. I have already passed the book onto a friend in the same position.'

Caroline was impressed by the way Ted's story was told and how pictures were used to help this.

'The book cleverly intersperses photographs of various periods throughout Ted's eventful life that encourage the reader to form a personal connection,' she says. 'I found the more recent images of him outside Abbey Road studios with his wife Linda and Simon to be very triumphant but also moving.'

'From the middle to the final chapters, the full effect that Ted's Alzheimer's has on his world and family is vivid.'

Pat says, 'For me, being able to recognise some of the experiences that Simon had encountered, all I wanted to do was to give him a "virtual hug" and reassure him that he is doing his very best for someone who obviously means so much to him.'

Honest

Tracy King, an activities co-ordinator at a Sheffield care home, recommends the book as an honest account of living with someone who has dementia.

'What a beautiful story of joy and heartache and pure determination to carry on and not give in,' she says, 'sometimes making mistakes but continuing to love and forgive no matter what. I'll be passing it onto my colleagues at work to read.'

For Gloria, the role that Ted's continued love of music played was something that resonated with her own experiences.

She says, 'I do believe music helps, as I have managed to turn one of our rooms into a music room for my husband with all his old CDs and LPs where he gets lost in memories of times gone by.'

Pat underlines the book's potential to inspire as well as educate.

'For those who do not know about, or have little knowledge of, dementia,' she says, 'this story is a truthful account of what it can be like to live on a day-to-day basis with a condition that so often is beyond your control.'

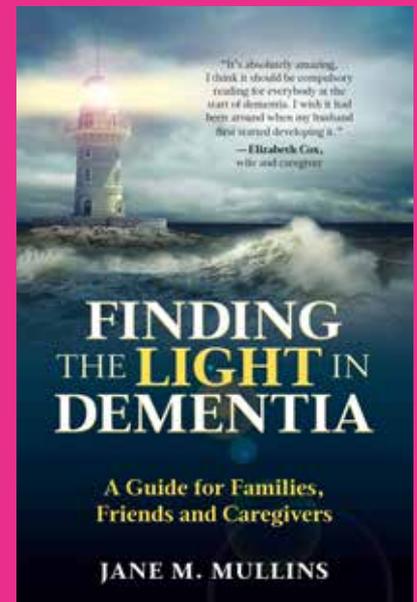
'And for those who are already living with or have lived with dementia, it is a reminder that, even though at times life can be so difficult, it is important to remember that there is more to the person than dementia.'

'The story that has been given such a high profile in the media – of Ted and Simon enjoying themselves and providing enjoyment for many others with their car karaoke sessions – is a relatively small part of the book, but such a positive and inspiring end to an account of real life that shows everyone that it is possible to live well with dementia.'

The Songaminute Man,
by Simon McDermott
(HQ, 2018), 256 pages,
£16.99, ISBN: 9780008232627.

An audio version from Audible is also available, list price £7.43 – see www.amazon.co.uk

Your turn



For the next issue, we invite you to read *Finding the light in dementia: A guide for families, friends and caregivers*, by Jane M Mullins (DUETcare, 2017), 226 pages, £12.99, ISBN: 9781999926809.

Let us know what you think about this book by 9 July 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 15 June quoting 'Light' for a chance to win one (see p39 for terms and conditions).



Talking Point members share advice about making their home a more dementia friendly environment.

Dementia-friendly home

'I have tried to keep everything free of clutter and I deliberately put a photo of my other half's mum opposite her chair for reassurance when she gets that "wanting to go home" feeling. It has generally worked, though there was a time when she started wondering if her mum was still alive.

'We are lucky with the layout of our flat in that the toilet is directly opposite the lounge, which reduces the chance of getting lost or wandering. It's also en suite, with another door from the bedroom to keep everything simple.' **naesporran**

'I close curtains and turn lights on as soon as daylight starts to fade, as my wife can confuse shadows or reflections with people in the apartment. I leave a hall light on overnight so that there is a crack of light at the bedroom door to make it easier to find and then light to find the bathroom once in the hall.

'I put stickers on kitchen appliances and remote controls to ease their use. I use a noticeboard in the kitchen to list activities and appointments.

'My wife, who has Alzheimer's, functions pretty well with these things.' **karaokePete**

'To help Mum accept a commode in her bedroom, when not in use there is a Victorian screen around it. Glass and pottery storage jars have been replaced with plastic or metal – pull top rather than screw – with labels of contents all around so, however they are put back, they can still be seen.' **Tin**

'Don't regularly change things around too much so as to keep familiarity. Keep clutter to a minimum. Make sure pathways are wide enough and free of obstructions.

'Colour contrasts are good. White on white might not be seen. Red is a good choice for plates and toilet seats. Keep rooms well lit in the evening and close curtains. Night lights will help too.

'Reminder tools and clocks only work up to a certain stage – don't get disheartened if they are

ignored, and only invest in expensive gadgets if you are certain they will really help.

'Some people with dementia don't like mirrors as they don't recognise the person looking back at them. Remove or cover them if that is the case.

'Get an occupational therapist to check out the place. They can make recommendations and often provide free things like grab rails, shower seats or boards, bed levers, wipe-able mattresses, booster cushions, armchairs or small tray tables.' **Beate**

'Just bought a 'Weekly Memo Board' which hangs on the kitchen wall just above where my other half keeps his wallet etc ready for when going out – he cannot miss seeing it.

'This board has the days of the week, and under each day a little wooden clothes peg. I can then peg a note on the relevant day saying what he has to remember that day. When the pegs are empty he knows he can do as he likes, when there is a piece of paper it is so obvious – not like just writing on a board – he sees it and can also take the note down and put it in his wallet if it is an appointment he has to remember.

'I bought this in a shop – nothing to do with dementia – but it works really well.' **maryjoan**

'To keep our home dementia friendly for myself and family, from the day of my diagnosis with dementia I took positive action and decided to keep my brain active by making the healthy part of the brain compensate for the damaged part.

'I have a white marker board in the office to write notes, I also keep reminders and notes on the iPad and iPhone.' **Countryboy**

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



Next issue

Do you have any tips about getting the right continence products for a person with dementia? Email magazine@alzheimers.org.uk or write to the address on p3.



Sports and exercise

Many people enjoy sports, and regular physical activity is important for us all to keep fit and well. Taking part in a sport or other exercise can often also provide opportunities to stay in touch with friends or meet new people.

A dementia diagnosis may be isolating, but continuing to socialise and be active can make a big difference. Adults are recommended to do both aerobic and strength exercises regularly to maintain health and wellbeing – visit www.nhs.uk/livewell for guidance – and the right sport or session can offer an enjoyable way to do this. Side by Side volunteers (see alzheimers.org.uk/sidebyside) can also support a person to carry on doing the sports and activities they love or to discover new ones.

Some people are used to regular exercise, but if not then it's worth checking what kinds could be suitable with a healthcare professional first, especially if you have other health problems. If you feel pain while exercising then you should stop, and exercise isn't recommended if you're tired or ill.

As dementia progresses, there are many gentler or seated exercises that could continue to provide activity and enjoyment.

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

Tips to improve your daily living at home

'Making your home dementia friendly' is full of practical tips on you can improve your home environment to make daily living that bit easier.



Order your free booklet today by calling **0300 303 5933** or emailing orders@alzheimers.org.uk and quoting code 819.

HELP BEAT DEMENTIA

**Register your
interest in dementia
research today**



Join Dementia Research allows people to register their interest in volunteering for dementia research studies. People with dementia, carers or anyone interested in research can find out about participating in studies.

Sign up today

Phone: 0300 222 1122 (local rates apply)

Online: www.joindementiaresearch.nihr.ac.uk

Womenswear competition

We have a soft pink 'Camilla' shirt, a gingko print 'Linda' wrap top and blue 'Anna' socks from the Able Label (see p30) as first, second and third prizes for winners drawn from correct entries received by 9 July.

Q: In the long-running TV series *The Muppet Show* and its associated films, the chicken who is also Gonzo's love interest is called:

A. Camilla.

B. Linda.

C. Anna.



Send us your competition answers for us to receive by 9 July, along with your name, address and telephone number – email magazine@alzheimers.org.uk or post to Magazine Editor, Alzheimer's Society, 43–44 Crutched Friars, London EC3N 2AE.

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.

Cupcake Day apron competition

Cupcake Day aprons were won by E Smith in Dorset, N England in Nottinghamshire, and A Cornwall in Surrey.
Answer: In the US, icing on cakes is often called frosting.

Reusable signage competition

A set of reusable signage stickers was won by B Dormer in Mid Glamorgan, while runners-up J Bubb in West Midland, M Quirke and A Bloomer in West Yorkshire, P Bladon in Worcestershire, R Crozier in Oxfordshire each received key fobs. Answer: In 1389, all pubs in England were required to hang signs outside their premises to make it easier for passing inspectors to check the quality of ale.

Book giveaway

The five readers who each won a copy of *The Songaminute Man* by Simon McDermott were W Utz and G Potter in Greater London, J Mountain in West Yorkshire, TE King in South Yorkshire and P Norris in Greater Manchester.



Who will you walk for?

1 in 3 of us will be affected by dementia.
Walk with us and raise funds for research.

Sign up at
memorywalk.org.uk

Alzheimer's Society operates in England and Northern Ireland.
Registered charity no. 296645

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