Tell dementia to jog on!

Sign up to jog, walk or run 26.2 miles whenever and wherever you like.

Complete the distance in days, weeks or months. The finish time doesn’t matter. It’s about raising vital funds to help finish dementia.

Sign up at jogondementia.org.uk
Welcome

Alzheimer’s Society turns 40 next November, and we launch our anniversary year at the Carols at Christmas concert in St Paul’s, London on 18 December.

We were founded by a small group of people who were determined to create real change for everyone affected by dementia. We’ve achieved a huge amount together since then, but it’s no secret that there’s much more to do.

The magazine is full of ideas and opportunities to make a difference, for yourself and for others. We want everyone who can benefit from these to subscribe, so please make sure your friends, family and colleagues know how (see below).

Danny Ratnaike, Magazine Editor

Questions about dementia? See p38

This is the December 2018/January 2019 issue of Dementia together, the magazine for all Alzheimer’s Society supporters and people affected by dementia.

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The countdown is on to our 40th anniversary next year. November 2019 will mark 40 years of Alzheimer’s Society supporting people and campaigning for change.

We now have over 20,000 volunteers and have created over 2.7 million Dementia Friends. Together, we’re making more than 330 communities dementia friendly. We’ve championed research from the start and have invested more than £60 million into dementia research since 1990.

Our vision is a world without dementia, and in the meantime we continue to fight for better support and a fairer care system. An incredible 135,000 of you campaign with us to make sure that dementia is prioritised.

Our 40th anniversary provides an opportunity to recognise our achievements and to say thank you for your support – we couldn’t have come this far without you. However, we still have a long way to go before we win our fight against dementia.

Our flagship Carols at Christmas concert, at St Paul’s Cathedral in London on 18 December, will launch a year of events to mark the anniversary. Comedian David Walliams and actor Carey Mulligan will take part alongside a special performance from Beaconsfield Singing for the Brain group.

For St Paul’s tickets, with a 50% discount available for people with dementia (under-16s go free), see alzheimers.org.uk/carolslondon or call 0330 333 0804 (local rate).

Dementia Connect: Now in Wales

Our new and growing Dementia Connect service, designed so that everyone affected by dementia can get the support that’s right for them at the right time, is now available in parts of Wales.

Dementia Connect combines our face-to-face, telephone, print and online support and advice, and we keep in touch to make sure people get the help they need as their needs change. It also brings people with dementia together with volunteers through Side by Side, supporting them to continue doing the things they love in their community.

We’re introducing Dementia Connect gradually to make sure we’re implementing it the right way, beginning in East Lancashire in 2017 and in Birmingham and Solihull in the spring of 2018. We have now launched it in selected areas of Wales, with more to follow.

Dementia Connect is key to us realising our ambitious five-year strategy to be there for everyone affected by dementia in England, Wales and Northern Ireland by 2022.

This new service isn’t available nationally yet – to find support near you, visit alzheimers.org.uk/getsupport

Read us in Welsh

The online version of our interview with Nigel Hullah (see p8) is also available in Welsh. Nigel, originally from Cardiff and now in Swansea, was diagnosed with posterior cortical atrophy in 2012.

A recent report by the Welsh Language Commissioner and Alzheimer’s Society Cymru – Welsh speakers’ dementia care – underlined the need to better meet the needs of native speakers in Wales.

To read our online articles, visit alzheimers.org.uk/magazine
We’re right to ask what Brexit will mean for research collaboration, access to drugs and the availability of critical nursing and care staff. We can leave it to history to judge David Cameron for his role in it, however his 2013 G8 summit on dementia set clear goals for 2025, including for a breakthrough drug treatment and transformation in awareness and support.

This December, the World Dementia Council meets in London to review progress and see how we can meet the 2025 goals. Despite increased research, a Global Action Plan from the World Health Organization and other progress, the World Dementia Council is challenging us all to do more. A new treatment remains elusive and, even in wealthier countries, the Global Action Plan has not been enacted.

We are proud of what Alzheimer’s Society has achieved – co-founding the UK Dementia Research Institute, creating over 2.7 million Dementia Friends and inspiring similar initiatives in 40 other countries, as well as rolling out a New Deal on Support.

However, the World Dementia Council is right – even as the Society marks our 40th anniversary in 2019, we need to do more. Too many still face dementia alone and we desperately need new treatments. Your support in this is vital, so thank you for all you’ve done in the past year and will do in the next.

Jeremy Hughes
Chief Executive Officer

Barbara Windsor joins the Dementia Revolution

Dame Barbara Windsor and her husband, Scott Mitchell, are backing our Dementia Revolution campaign to raise money for ground-breaking dementia research.

Dementia Revolution, a partnership between Alzheimer’s Society and Alzheimer’s Research UK, is Charity of the Year for the 2019 Virgin Money London Marathon.

Scott, who earlier this year revealed that much-loved actor Barbara had been diagnosed with Alzheimer’s in 2014, will be running the marathon himself.

He said, ‘I don’t know how fast I will run it, but for me it is more about completing the marathon, no matter what the time, to show my support for Barbara and all the other people living with dementia across the country.’

In a message to everyone running for the Society, Barbara said, ‘With your help, we can and will end dementia with research.”

Dementia Revolution aims to raise £3.5 million for the UK Dementia Research Institute, which is bringing world-leading expertise together to fight all forms of dementia.

New care home booklet

Our latest booklet – Selecting and moving into a care home – is written for carers and family members, and may also be useful for people with dementia who want to plan ahead. It explains the process and includes checklists of things to consider, with tips for moving in and handling challenges.

To order Selecting and moving into a care home (690), visit alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
In the press

From the womb?

In recent months, we’ve seen newspapers proclaiming that dementia may begin in the womb, though these dramatic headlines don’t tell the full story.

The idea came from a small research study looking at the brains of 20 people who had lived with Alzheimer’s, 20 with dementia with Lewy bodies and 14 who had died without having dementia. The researchers were interested in mutations in genes that can occur when cells in our body divide, but don’t pass information on correctly to the new cells.

The study suggested that dementia could start from brain cells containing a mutation within particular genes. Unusually for cells of the body, most of the dividing that brain cells do is completed while we’re babies, hence the headlines.

Although this is an interesting idea, it has limitations. The study’s small size means that it’s not reasonable to draw firm conclusions from it. Researchers also found the particular genetic mutations in the brains of people who didn’t have dementia, which weakens their argument.

Finally, some of these mutations were found in places where we already know dementia doesn’t start to develop.

Alzheimer’s Society-funded researchers are working hard to learn more about inherited and non-inherited genes that could cause dementia, in part through our support of the 100,000 Genomes Project. Visit alzheimers.org.uk/research to find out more about our research.

Cardiff launch

The UK Dementia Research Institute has officially opened its centre at Cardiff University. Cardiff is one of six hubs across the UK working on dementia research as part of the £290 million institute.

Up to 100 scientists in the Welsh capital will be investigating subjects such as genetics and the brain’s immune system to discover more about the causes of dementia and how it could be treated.

The UK Dementia Research Institute, part-funded by Alzheimer’s Society, is a core element of the New Deal on Research, a key strand of our ambitious five-year strategy.

Dementia Friendly Award winners

Winners of this year’s Dementia Friendly Awards were revealed at ceremonies in London and Belfast at the end of November.

The awards celebrate the achievements of individuals, groups and organisations who have led the way in creating dementia-friendly communities and improving people’s lives.

Queen’s Film Theatre was one of eight winners in Northern Ireland. It provides monthly dementia-friendly screenings in Belfast and was named Dementia Friendly Organisation of the Year among smaller and medium-size entrants.

The 81st Belfast Beaver Colony were named Youth Organisation of the Year for their fundraising, awareness raising and visits to local people living with dementia.

The Outstanding Contribution of the Year award went to Gerardine Mulvenna, who has been using her position on the local council to ensure that Larne becomes a dementia-friendly town.

The 10 winners across England and Wales included Charlie Phillips, an 11-year old boy who won the Uniting against dementia – Outstanding Contribution award for his proactive awareness and fund raising.

Sarah Williams-Martin, chair of Bath and North East Somerset Dementia Action Alliance, was named Dementia Friends Champion of the Year. As well as creating hundreds of Dementia Friends, Sarah launched a training programme to get others involved in the local alliance.

The Championing Diversity award went to Touchstone, a health and wellbeing charity in Yorkshire that runs a dementia café for people from South Asian communities.

See alzheimers.org.uk/dementiafriendlyawards for more on all of the amazing winners.

Leaving a legacy

Look out for our new campaign in January encouraging people to leave Alzheimer’s Society a gift in their will. TV and radio adverts will feature Denise Wilton, a supporter and Dementia Friends Champion whose father has dementia. She shares how dementia has affected her life, and explains that she is leaving a legacy in the hope that her daughter and later generations can have a future free of dementia.

To find out more, visit alzheimers.org.uk/legacies or call 0370 011 0290 (local rate).
Come to our 2019 conference

Alzheimer’s Society Annual Conference is returning to London’s Kia Oval on 21–22 May, and we want as many people affected by dementia as possible to take part. Attending is a must for anyone working in health and social care, local and national government, policy and research, so it’s vital that people with dementia and carers are also there to share their experiences and have their say.

Registration opens in January but you can register your interest before then to receive promotional offers.
To register your interest, visit alzheimers.org.uk/conference or call 020 7423 3650.

Budget: Not enough

Alzheimer’s Society says the recent Budget announcement was a missed opportunity to end the social care crisis. Chancellor Philip Hammond pledged additional money to help local authorities with social care, but this will not address injustices for people affected by dementia.

Jeremy Hughes, our Chief Executive Officer said, ‘£650 million to prop up the broken social care system only just staves off total collapse. It does nothing for people with dementia who are footing the bill themselves, while people with other conditions are getting free support through the NHS.

‘We’re told austerity is over, but people living with dementia have been forgotten, and the Budget was a missed opportunity to end this injustice. Now the pressure is on for the government to create a properly funded and joined-up system that can deliver high quality dementia care.’

Unite with us to fix dementia care at alzheimers.org.uk/fixdementiacare

Record-breaking Memory Walk

We’d like to say a huge thank you to everyone who made this year’s Memory Walk such a great success. Over 100,000 people came together to walk towards a world without dementia and celebrate loved ones, raising £6.5 million and counting. An incredible 2,600 volunteers made these walks possible.

Many of you have also been holding your own walks as part of Your Walk, Your Way. We have had over 3,800 organisers raising £380,000 so far.

Christmas carol concerts

There’s still time to unite in song against dementia by attending a Carols at Christmas concert this December.

As well as our flagship London event at St Paul’s Cathedral on 18 December, concerts are taking place at impressive venues in Birmingham, Sheffield, Norwich and Bury St Edmunds during the second half of the month.
To book tickets, please visit alzheimers.org.uk/carolsatchristmas or call 0330 333 0804 (local rate).

In briefs

Listen online or on CD

Many of our most popular factsheets are now available to listen online or on CD, including What is dementia? (400) and Carers: Looking after yourself (523). These join our audio versions of other information as well as magazine stories.
Listen online at alzheimers.org.uk/audioandvideo or call 0300 303 5933 (local rate) to order CDs.

Music memories

A new BBC website aims to reconnect people with dementia with the music they love and to help them create playlists.

BBC Music Memories, a collaboration with the charity Playlist for Life, offers around 1,800 clips of songs, classical works and TV theme tunes from the last 100 years.
Visit musicmemories.bbcrewind.co.uk

Argos and Wilko collections

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We are the storm

When people are denied basic human rights, Nigel Hullah believes in the power of a shared voice. Gareth Bracken meets a man with dementia who wants everyone to have their say.

Quick read

Nigel Hullah, a former human rights lawyer, is demanding that people affected by dementia have their rights recognised and respected.

Nigel, who lives in Swansea, was diagnosed with posterior cortical atrophy, a rarer form of dementia, in 2012.

He wants people affected by dementia to unite to influence lawmakers and service providers.

He benefits from a local peer support group and doesn’t want anyone else to feel left behind by the dementia movement.

Hear Nigel’s story
Listen to this and previous stories at alzheimers.org.uk/podcast
I think the time has come to make a real political statement over dementia – to make MPs and ministers a little bit afraid of us,’ says Nigel Hullah, 57, who has been living with the condition for six years.

A former human rights lawyer from Cardiff, Nigel wants people affected by dementia to unite to demand change in how others see and support them.

Lost hours
Nigel, who now lives in Swansea, became aware he had a problem that needed to be addressed when he ‘lost’ hours from his day. He was working for a charity at the time, in a role that involved early morning starts.

‘I’d put the news on at 5.30am and the next thing I knew it was quarter to six, quarter to seven. Then it was four in the afternoon and I’d have no recollection of that time loss,’ he says.

Following a ‘tortuous four years of pre-diagnostic rigmarole’, Nigel was diagnosed aged 52 with posterior cortical atrophy (PCA), a rarer form of dementia, in 2012.

‘I now have to factor in an extra hour, in case I wake up and something’s gone missing from my mind again,’ he says.

‘I look at the coffee machine and think, “How does that work?” Or I look at my shoes and wonder how my laces work. No two days are exactly the same.’

Lesser person
Nigel found his diagnosis ‘truly shocking’, but was more disturbed by how society now viewed and treated him.

‘Everybody saw me through the prism of dementia – I stopped being a person,’ he says.

‘I felt my human rights had been taken away from me. Banks, statutory bodies and justice departments all felt I was a lesser person because of the presence of dementia. That made me quite angry.’

Nigel, who lives alone, says this caused him to ‘sink into some deep depression’.

‘My day consisted of getting up in the morning, and drinking and eating until I fell asleep. I ordered my food online. My weight ballooned to 30 stone and I was totally immobile. I dropped off from friends and family, and became socially isolated.’

He credits his turnaround to occupational therapists from the local young-onset dementia team.

‘Had that carried on, I suspect I wouldn’t be here now. But they turned up at my door and “attacked” me with all the vigour and fervour of a religious crusade,’ he says.

‘They threw stuff out of my fridge and colluded with my friends, family and neighbours.'
‘I think occupational therapists are the magic bullet – they build on what you have and enable you to do things.’

Powerful voice
As Nigel’s understanding of his new situation came into focus, he grew increasingly angry at how people with dementia are treated.

‘For me, I think dementia is wholly a matter of human rights,’ he says.

‘On diagnosis, we are routinely placed with a community mental health team, even though there’s no presence of a mental illness. That’s human rights infraction number one.

‘Equity in healthcare, law, employment – they all disappear.’

He recalls having to get support from a voluntary agency on a tax issue, because HMRC staff wouldn’t deal with a person with dementia on their own.

‘It’s these slight, subtle changes,’ he says. ‘We’ve all got human rights and they shouldn’t dilute with age or evaporate in the face of frailty or disease. If we don’t use them, then they will be diluted.’

Nigel is also demanding better from those who oversee dementia care and support.

‘When service planners say that they’ll try to adopt a human rights model, that isn’t good enough,’ he says. ‘You’re expected to treat me exactly the same. You’re not doing me any favours – it’s the law.’

Nigel feels that people affected by dementia have yet to realise the power of their own voices in demanding that their rights be recognised and respected.

‘If there’s 850,000 people in the UK with dementia, and for each of them there’s 10 other friends or family affected by it, that’s 8.5 million people,’ he says.

‘Imagine if you politicised them, gave them a voice.

‘We could go to lawmakers and service planners and say, “I am part of the constituency of people with dementia – you will not use my condition to deny me my human rights.”’

Social movement
Nigel is adamant that people living with dementia should be at the centre of discussions about how services are provided.

He highlights the impact of people in Wales sharing their experiences of dementia with the Welsh government ahead of the country’s Dementia Action Plan.

‘In May 2016, the Welsh Cabinet Secretary for Health said that the voices of people with dementia had changed their minds about the services we’re going to provide,’ he says.

‘That action plan is a fantastic example of what happens when you involve the people who are going to be in receipt of these services.

‘Given the opportunity, we can get fired up, we can be ready to go. We can go to our lawmakers and say, “We don’t want what you think we want – this is what we want.”’

Nigel is also part of the 3 Nations Dementia Working Group (3NDWG), a network of people living with dementia in Wales, Northern Ireland and England. They aim to use their personal experiences to become the ‘go to’ group for anyone seeking input from people with the condition.

‘We’re pushing social change to the forefront of our agenda. I want the dementia world to be a social movement,’ he says.

‘We want to bring to people’s attention things like the broken social care system, a benefits system that isn’t fit for purpose, and the lack of opportunities for people with dementia to utilise transport, education and healthcare.

‘We’re the steering group and we want to have thousands of associate members, so that when we get things going we have that strength of voice to really make an impact.’

Everyone involved
Nigel has been involved with DEEP, the Dementia Engagement and Empowerment Project, which brings together groups of people with dementia from across the UK to influence the services and policies that affect them. He also sits on a number of advisory groups and shares his experiences at events and conferences.

But he says that none of this would be possible without the backing of his friends at Fuse and Muse, the peer support group he attends in Swansea.

‘Sometimes dementia whispers in my ear, “Nigel, you ain’t strong enough to withstand the storm.” But one phone call, conversation or meeting with my group and I’m able to say to dementia, “I am the storm.”

‘There is no support like peer support – it has saved my life.’

As he plays his part in rallying the growing dementia movement, Nigel wants to ensure that no one is left behind.

‘I want everyone to have a say, everybody to have a view,’ he says. ‘I want everybody to feel valued and wanted – that’s the key. Nobody should feel marginalised or abandoned.

‘We’re all important. We’ve all got something to offer.’
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.

Next steps

- Unite with us to help fight dementia – find out how at alzheimers.org.uk/getinvolved or call 0330 333 0804 (local rate).

- For our Rarer causes of dementia (442) factsheet, go to alzheimers.org.uk/factsheets or call 0300 303 5933 (local rate)

- For more about the 3 Nations Dementia Working Group, visit www.3ndwg.org
A Alzheimer’s Society was formed in 1979 to provide support and raise awareness, and we’ve championed research from the outset. Through our Research Network, people affected by dementia contribute to every stage of research into the condition.

Established in 1999, the network now includes over 280 carers, former carers and people with dementia. They play an active role in deciding what research we fund, as well as monitoring ongoing work and sharing results.

Barbara Woodward-Carlton, whose mother had Alzheimer’s, is a founding member of the network and has seen huge change over the years.

‘When the Research Network first launched, the idea of patient and public involvement in dementia was barely acknowledged,’ she says. ‘As our reputation grew, Research Network volunteers have had many more opportunities to be involved with projects funded by other organisations.’

Take back power
Paul Gill was diagnosed with frontotemporal dementia in March 2013. After being supported by the Society, he and his wife Kathy (pictured) decided to give something back by joining the Research Network.

‘It’s so empowering for both of us,’ says Paul. ‘We have a voice and can use our experiences to create real change for others. It helps us to feel respected, valued and useful, which people with dementia don’t always get to feel.

‘It gives us the opportunity to take power back from the disease that’s threatening to take so much from us.’

Kathy, who is also a Dementia Friends Champion, adds, ‘We really feel like we are making a contribution to society.’

Open to all
The Research Network will work with the recently established UK Dementia Research Institute, a key feature of our current strategy. You don’t need any qualifications, scientific knowledge or research experience to volunteer.

‘We want people from all backgrounds and communities to join our vibrant and active network,’ says Anna-Louise Smith, Research Engagement Manager.

‘More and more researchers are including people affected by dementia in their research, because they understand that it’s the right thing to do and improves the quality and relevance of their work.’

Looking ahead, Barbara believes the Research Network will continue to help bring about better dementia knowledge and support.

‘Good quality, evidence-based research improves the quality of life of those with the condition and their carers,’ she says.

Anna-Louise says, ‘Together, researchers and people affected by dementia can ensure that research will have the best chance of making a meaningful difference to people’s lives.’

For more about the Research Network and to volunteer, visit alzheimers.org.uk/researchnetwork
Just a start

A Dementia Friends Champion in Wiltshire wants even more people to help transform how we all think, act and talk about dementia.

Kevin O’Donoghue admits to feeling ‘a bit daunted’ before running his first Dementia Friends information session with a classroom full of schoolchildren. However, ideas and support from other Dementia Friends Champions gave him the edge he needed.

‘It was brilliant. The school was covering the brain as part of the curriculum, so we piggybacked onto that. They were all very receptive. Some of the actions agreed at the end of sessions were notable. One lad said he was going to find a cure! They listen, they pay attention. It means something to them – they have grandparents who have dementia.’

Obvious topic

Kevin, in Highworth, Wiltshire, became a Dementia Friend in 2017 and trained as a Dementia Friends Champion that summer. Having retired from work, he wanted something constructive and meaningful to do with his days.

‘It was time to pay back and do some volunteering. Dementia seemed a fairly obvious topic to focus on, bearing in mind that it’s a growing issue.’

Although most of Kevin’s information sessions have involved up to 10 people, school visits have boosted the number of Dementia Friends he’s created overall. In fact, Kevin recently joined the 167 Dementia Friends Champions who have signed up more than 1,000 people to the social action movement.

He credits Susan Lambert, Dementia Friendly Co-ordinator at Swindon Council, with helping to organise so many sessions.

‘Basically, she’s my agent. She gets most of my gigs!’

Meeting another Highworth-based champion, Elaine Graham, also had an impact.

‘We’ve done several joint sessions since, which is good. You learn from other people. It’s not often that you get to see another champion doing a session. It’s very useful, because we all do it slightly differently.’

He says the impact of the information sessions on new Dementia Friends is clear to see.

‘You can see enlightenment dawning and hear the pennies dropping, especially on the importance of visiting relatives with dementia.’

Keep growing

There are now over 2.7 million Dementia Friends, but Kevin is determined to do his bit to keep the movement growing. ‘It’s fantastic that so many people have joined, but it’s just a start really. We need to reach a lot more people to reach a tipping point in levels of understanding about dementia and how it affects people. For me, it’s the best thing I’ve done in years.’
In many ways, Paul Eatwell’s approach to life embodies the spirit of our Side by Side service. ‘I have always tried to stay positive and to look at life in terms of what I can do rather than what I can’t,’ he says. ‘It seems to me that Side by Side is an opportunity to put that into practice.’

‘I wanted to do something positive and, even if only in a very small way, to help someone with dementia to stay positive and continue to do the things that they have always enjoyed – to live as full a life as possible.’

Real connection
In the spring of 2017, East Lancashire became the first area for us to introduce our new service, Dementia Connect. As part of this, Side by Side connects volunteers with people who have dementia, so they can support them to keep doing the things they enjoy.

Paul, a Dementia Friend in Blackburn with Darwen, was put in touch with Wayne Smith after becoming the area’s first Side by Side volunteer. Now aged 63, Wayne was diagnosed with Alzheimer’s six years ago.

Paul says, ‘I think we were both a bit nervous when he originally agreed to trial the service, but we have developed a firm friendship.

‘Wayne has always enjoyed walking and drinking coffee. We generally head out to a nearby coffee shop, chatting about life, the universe and everything, and enjoying the countryside and the changing seasons.

‘Wayne and his wife have placed an enormous amount of trust in me by allowing me into their lives, but what began as an assignment has become a real friendship.’

Positive impact
Rebecca, Wayne’s wife, has no doubt about the positive impact of Paul’s visits on her husband.

‘It gives him company,’ she says. ‘It also gives him someone to chew the fat with.’

She’s also conscious of Wayne’s need to talk about his dementia to someone other than her.

‘It benefits Wayne to speak to someone about it. I know he feels sad for me sometimes and I think that stops him talking to me about it. It’s not the easiest thing to talk about.’

Paul says, ‘Being a Side by Side volunteer has improved my listening skills and made me think more broadly about how I relate to people in everyday life. It also gives me a buzz to feel that I’m doing something positive for a friend.

‘Dementia doesn’t automatically mean the end of independence and enjoyment – it’s a diagnosis, not a sentence.’

A full life
A Dementia Friend in Lancashire has found friendship and meaning with a local man who has Alzheimer’s through Side by Side.

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.
Everybody has a story to tell, and it’s my role at Alzheimer’s Society to support people who want to share their personal experiences of dementia.

We can, and we will, talk about dementia facts and statistics until we are blue in the face. However, it’s real-life experiences – like those featured in this magazine – that really strike a chord with many people and motivate them to take action.

Sharing powerful personal stories in the media, online and elsewhere, raises awareness, challenges stigma and highlights the support that we offer.

The best bit of my job is meeting some amazing people with dementia who decide to make a difference for others by speaking out. This can bust myths while also encouraging people to donate and to get involved in the cause.

This can be emotional, but we have lots of laughs too. It’s wonderful to see people speaking from the heart on a breakfast TV sofa or in a newspaper interview, defying the stereotypes and, best of all, enjoying themselves.

My many conversations with carers and family members can be harder. Understandably, there’s a lot of anger and frustration as people struggle to find and fund suitable care for their loved ones. However, sharing these heart-breaking experiences adds weight and power to our ongoing campaigns.

The more stories we tell, the bigger the difference we can make for everyone affected by dementia.

If you’d like to tell me about your experiences please do get in touch at alzheimers.org.uk/share

Subscribe to Dementia together magazine today

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

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

Their walk, their way

A family in County Down got well-deserved thanks from their mayor after raising over £4,300 through their own Memory Walk.

Jack and Kathleen Cash arranged their own event through Your Walk, Your Way on the suggestion of their youngest daughter, as they weren’t able to make their nearest organised Memory Walk. Jack, who has vascular dementia, walks around 12 miles a day and plays table tennis twice a week, and the couple were determined not to lose the opportunity to take part.

Over 100 people joined the family’s walk in Newtownards in September, and the Mayor of Ards and North Down, Richard Smart, acknowledged their dedication with a reception at the town hall.

Apart from being grateful for the recognition, Kathleen said, ‘It also drew awareness to the issue of dementia by being covered in the local newspaper.’

LGBT+ and dementia

A support group for lesbian, gay, bisexual and trans (LGBT+) people who are living with dementia in Greater Manchester and surrounding areas now meets every month.

Run by LGBT Dementia Network, supported by local lead dementia nurses and Alzheimer’s Society, meetings take place at LGBT Foundation in Manchester and the next will be on 28 January.

For more information, email lgbt.dementia.network@gmail.com or call 0345 330 3030 (local rate).

Dementia choir on TV

Vicky McClure, the award-winning actor and Society Ambassador, has been working with researchers and a choir of people affected by dementia to explore the effects of music and singing.

The choir spent months preparing for a concert at the Royal Theatre Nottingham in September, and Vicky followed their highs and lows for a two-part BBC TV special called My Dementia Choir, expected to be broadcast later in 2018. The documentary will also feature what the researchers could find out about the impact of being involved on people living with dementia.

Whatever may or may not be visible in brain scans, the benefits have been real enough for choir members, who have continued to meet since filming ended.

Shining a light

Tony Husband, the award-winning cartoonist, has teamed up with Exeter Dementia Action Alliance to produce a calendar to raise awareness of dementia and its impact on people’s lives.

The calendar, called Shining a Light on Dementia, is supported by a range of organisations involved in the local alliance. It features illustrations in Tony’s immediately recognisable style that underline what everyone can do to help support people affected by dementia in their community.

Gina Awad, who leads the alliance, said, ‘We wanted to raise dementia awareness through a creative medium that would touch everyone and involve our members.’

To order a calendar for £8, including postage and packing, email exeterdaa@outlook.com
Over 2.5 million people have become Dementia Friends. Will you join them?

Visit dementiafriends.org.uk to get involved
I understand intellectually why Mum is the way she is, but it’s totally different to accept it emotionally,’ says Ming Ho, whose mother Glenys has dementia.

Glenys, 92, was diagnosed with mixed dementia – Alzheimer’s and vascular dementia – in 2011. Her condition has totally changed their mother–daughter relationship, leaving Ming to wonder how she can tap back into what they once had.

Warm and friendly
Glenys was born in Chorley, Lancashire to parents from north Wales and always considered herself Welsh. She was a professional classical singer who performed at concert halls, cathedrals and on BBC radio broadcasts. After getting married she became a school teacher, though continued to train others in singing.

‘She was always very warm, generous and friendly,’ says Ming. ‘She was very empathetic – almost too much. She would be the first to help someone in trouble. She was also a bit of a joker and had a great sense of humour.’

Ming, originally from Gloucestershire but now living in north London, was the only child of Glenys and her husband, Wai Kwong Ho, a nuclear physicist from Shanghai in China. Wai Kwong died in the late 1980s, when Ming was still a student.

Extreme reactions
Ming has seen her mum’s behaviour and personality change drastically over the years. She thinks there were very early signs after Glenys lost her husband, retired and saw her daughter move away from home, all in quick succession.

‘She started having extreme emotional reactions to things,’ says Ming. ‘She became unnaturally possessive of me on occasion and felt threatened by my relationships with others.’

A neighbour died around 10 years ago, but Glenys didn’t show or seem to feel the kind of sympathy that could be expected.

‘She was strangely angry, defensive and resentful,’ says Ming. ‘The family put a note through her door to let her know the news, but she somehow saw it as an imposition. She said, “They can look after themselves!”’

Glenys would have moments of paranoia or delusion, becoming uncharacteristically antagonistic.

‘It came and went in flashpoints, so was very hard for any of us to grasp,’ says Ming.

She acknowledges how difficult it must have been for friends, especially as Glenys was yet to be diagnosed. However, Ming was still surprised and saddened that some chose to cut ties with her mother.

‘I can understand people being confused, but some we had known for 30 or 40 years were quite mercenary, even when I explained things,’ she says.

Crisis point
As things worsened, Ming’s attempts to call in support for both Glenys and herself were hampered by her mother, who didn’t think anything was wrong.

Ming Ho has been reflecting on how her mother’s dementia has affected their once close relationship.

Glenys, 92, lives in a care home, having been diagnosed with mixed dementia in 2011.

Ming finds it distressing when Glenys is rude or mistakes her for staff, considering the great history they share.

Ming hopes her loving words have an emotional impact on her mother, even if she doesn’t remember what is said.
‘She wasn’t eating or washing, and was getting into distress, but could present as normal when visited by professionals,’ says Ming. ‘She told a social worker, “What do I need a carer for?”

‘That had been my opportunity to get some help but she totally rejected it. I was dying inside. ‘I used to say she was in denial, but now I see that she was unable to recognise her condition.’

With Glenys’s needs coming first, Ming’s career went on hold. Having been a TV script editor, she had gone freelance as scriptwriter in 2000, writing for programmes such as EastEnders and Casualty.

‘I never intentionally gave up work, but when Mum reached crisis point I had to stop pitching and fell out of circulation,’ she says.

‘Thankfully I am now back in business, but for years there was so much going on with Mum, I didn’t have the time or headspace. Every day there was a crisis.’

**Agonising decision**

Glenys entered a care home in Gloucestershire in September 2011 and initially seemed to settle in well.

‘It was a big upheaval so I was hugely relieved that she accepted the home and was able to thrive there,’ says Ming.

But in 2015 the manager left and the feeling of the home quickly changed.

‘There was evidently an imperative to cut costs and maximise profit,’ says Ming.

‘The staffing ratio in Mum’s unit was cut by half and the continuity went.

‘Mum was admitted into hospital with aspiration pneumonia in the midst of this trauma. The situation was very upsetting.’

After much agonising, Ming decided to move Glenys in May 2018.

‘I struggled with it, as I worried that a move could kill her. But she’s settled well and seems as content as she can be anywhere,’ she says.

Ming makes the 200-mile round trip to visit Glenys almost every week, never fully knowing what to expect.

‘That’s been one of the hardest things to accept – the massive change in Mum’s personality,’ she says.

‘She can still have cheeky moments and is relatively articulate but she’s also much more withdrawn and suspicious.’

**Support and hope**

Having learned more about dementia from fellow carers and professionals on Twitter and Alzheimer’s Society’s online community, Talking Point, Ming has blogged about her own experiences at www.dementiajustaintsexy.blogspot.com

However, she still struggles with the feeling of losing her close connection with her mum.

‘I know not to expect her to react as a mother to me – if it happens it’s a bonus,’ she says.

‘But she sometimes talks to me as if I’m staff or a waitress, which I find tragic as we have a lifetime’s history.

‘Sometimes she’ll say nasty things. I try and rationalise it but it still hurts. I still have a cry over it.’

Some of these themes and feelings are explored in The things we never said, the award-winning Radio 4 play that Ming wrote about the relationship between a mother who has dementia and her daughter.

‘It wasn’t until Mum went into care that I stepped back and started thinking about the story I wanted to tell,’ says Ming.

‘Mum’s been everything to me and I’ve been everything to her. I was the centre of her world. We’re each other’s only close family. But now she doesn’t know who I am. The play was grappling with that. What is a relationship? How can that disappear? How can you tap back into it?’

Although she knows that their relationship can never return to what it was, Ming is determined to retain any essence of what she and Glenys once had.

‘Every time I leave I say, “Remember I’m always thinking about you.” I know she won’t remember but I hope it makes an emotional impression,’ she says.

‘Somewhere inside I hope she has an instinct of someone who loves her and cares about her. I don’t want that to be broken.’
Next steps

- Join Talking Point, our online community, at alzheimers.org.uk/talkingpoint

- For our range of publications about caring for a person with dementia, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

- Use our online directory to find dementia services near you – go to alzheimers.org.uk/dementiaconnect
Tackling dementia

A sports café in Worcester is providing people affected by dementia with physical activity and social support. **Gareth Bracken** visits a group that ensures everyone is included.

A game of tennis is in full swing by the side of the pitch at Sixways Stadium in Worcester, West Midlands. The nearby clubhouse is the venue for some impromptu indoor football, while a couple of therapy dogs are on hand for those who prefer some interaction with animals.

This is the Tackling dementia sports café, a free weekly group for people with dementia and their relatives or carers, run by Worcester Warriors Rugby Club. It offers members mild physical activity, mental stimulation and a chance to socialise.

The café is led by Simon Northcott, the club’s Disability and Inclusion Lead, who had the idea after becoming a Dementia Friends Champion.

“We plan it loosely – we don’t want to control people,” he says. Cricket and table tennis are also on offer, while some prefer to draw or simply chat over a hot drink. Within half an hour, dozens of attendees, staff and volunteers are engaged in physical and social activity.

**Bonding time**

Today is the café’s first birthday, with food and cake put on to celebrate. Trudie Jennings and her late husband Alan, who had Alzheimer’s, were one of two couples who attended the very first session last year.

‘Alan enjoyed it here so much,’ says Trudie. ‘He was quite reluctant to go to some places, but this took him back to his days of rugby and hockey. It’s quite unique.’

Nickie Attwood used to attend with her late grandad Stan Ballard, known as Pops, who had vascular dementia. He enjoyed playing skittles and football at the café and was the referee for some games.

‘He absolutely loved it here – he was full of smiles. It seemed to set his mood for the rest of the day,’ says Nickie, who also benefitted from attending.

‘It gave us bonding time and somewhere we could go together that wasn’t a hospital or doctor’s appointment.’

**Sense of purpose**

David Gunn, 86, who has dementia, attends the café with his wife Philippa.
‘There’s a space for physical activity, which is what attracts me,’ he says. ‘I still try and keep physically fit.

‘It’s also the fact that I’m not the only person in the world with dementia. I’m happy to socialise with people with a similar condition.’

Philippa agrees that David benefits from such interaction.

‘Since his dementia, he’s becoming more isolated at home, but he loves it here,’ she says. ‘It gives him a sense of purpose for the day.

‘The fact he’s in a good place also makes it easier for me.’

Anne Molloy has been visiting the café with both of her parents. Her mother Hilary, 87, was diagnosed with dementia seven years ago. Her father Pat, 92, doesn’t have dementia but loves rugby and used to play for Worcester in the 1950s.

‘Simon is so patient with Mum – he devises different games for her and encourages her with different techniques,’ says Anne.

‘Everyone is included and accepted here. Dad will push Mum round the pitch in her wheelchair. They feel part of it.’

Shirley Garbett attends the group with her husband Bill, 80, a keen former sportsman who has dementia with Lewy bodies.

‘Bill is much happier afterwards and it helps us carers too,’ she says. ‘We all know we’re in the same situation.

‘The group is brilliant, fantastic – you can’t describe it.’

**Living well**

The café is supported by a team of passionate volunteers. One of them, Edward Bunn, has hydrocephalus, which involves a build-up of fluid in the brain and can be a rarer cause of dementia itself.

‘I talk to people and help with the games. I’m just a part of the community,’ says Edward, 68.

‘I consider myself extremely fortunate that my situation is under control and I can help out. I think I have an understanding of where these people have been or are going.’

Val Wellings, a Dementia Friends Champion, is another volunteer at the café. She says the group helps its members to live well with dementia.

‘We’re providing the space, environment and people,’ she says. ‘It’s about tapping into their reality, what’s important to them.’

The café’s success was recognised at our 2018 Dementia Friendly Awards, where it was named a Dementia Friendly Organisation of the Year.

**Inclusive club**

Elsewhere at the club, one of the stadium’s corporate boxes has been given over as a safe place to people who want to watch the rugby in a less noisy or crowded environment.

Simon and Val have helped create over 100 Dementia Friends among the club’s staff, volunteers and players. The club is also part of its local dementia action alliance – organisations that have come together to make their community more dementia friendly.

‘The whole club’s values are based around inclusivity,’ says Simon. ‘The evolution of this project just never stops.’

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**Next steps**

- Visit [alzheimers.org.uk/dementiafriendlycommunities](http://alzheimers.org.uk/dementiafriendlycommunities) for more about dementia-friendly communities.

- For our Keeping active and involved (1506) booklet, see [alzheimers.org.uk/publications](http://alzheimers.org.uk/publications) or call 0300 303 5933 (local rate).

- Use our online directory to find dementia services near you – go to [alzheimers.org.uk/getsupport](http://alzheimers.org.uk/getsupport)
For the past year, the Society’s Innovation team has been asking the question, ‘How can we better support care home staff when it comes to the sex and intimacy needs of residents living with dementia?’

‘Sex and intimacy is a taboo subject in general, but when we add age, dementia and care homes to the picture it becomes further shrouded,’ says Beverley Page-Banks, Programme Development Manager.

Beverley says that, although care home staff have the best of intentions, a resident’s needs or rights might be ignored or denied. ‘They may still want to hold hands or cuddle with a loved one, to share a bed and maintain a sex life with a partner, or to seek a new partner,’ she says.

‘There are stories where this has been enabled. However, more often than not, care home staff get stuck in a cycle of concern about mental capacity and wanting to avoid any risk at all. ‘This is completely understandable, but it can restrict privacy, rights and choice for people with dementia.’

Workshop in a box
Beverley’s team visited care homes to speak with many staff and people affected by dementia, Over 70 ideas were drawn together to help staff approach this issue in a way that supports residents’ dignity and rights.

These ideas were whittled down, and prototypes of two of them were tested with care home staff. This convinced the team to combine them into one solution — a ‘workshop in a box’ called Lift the Lid that enables care homes to run sessions themselves.

Up to 10 staff at a time can take part in a session. This can last for two to three hours or be broken down into 45-minute sections. Although it’s mainly designed for care home staff, aspects could be adapted for residents and their families too.

Lift the Lid includes a True or False game, with 10 question and answer cards that challenge perceptions and provoke discussion. A second activity, Follow the Heart, uses scenarios and guidance to support important conversations with residents, partners and families. Another, Plan for Change, helps staff to pin down what will make a practical difference in their particular care home.

According to A care home in Grantham says the resource has helped its staff feel more relaxed about discussing sensitive subjects.

Four Seasons Health Care says that Lift the Lid has created a foundation for a shift in culture at their homes.

Quick read
Alzheimer’s Society has created a resource to help care home staff address the sex and intimacy needs of residents who have dementia.

Lift the Lid is a ‘workshop in a box’ that challenges perceptions, provokes discussion and offers guidance.

A care home in Grantham says the resource has helped its staff feel more relaxed about discussing sensitive subjects.

Four Seasons Health Care says that Lift the Lid has created a foundation for a shift in culture at their homes.

Breaking taboos

Sex and intimacy can be a taboo topic when it comes to people with dementia in care homes. Gareth Bracken reports on a new resource that’s supporting staff to deal with a sensitive subject.
Sensitive subject
Joanne Howcroft is a Bupa manager who has taken a lead on how her organisation meets the needs of care home residents who have dementia. She has been involved in the project for the past year.

‘It has been an interesting journey and a fantastic experience that has encouraged me to reflect on my own perceptions,’ she says.

‘The final product will help staff realise that relationships do not stop at a certain age or when somebody moves into a care home,’ says manager Denise Booth.

‘Lift the Lid helps open up a subject that we don’t talk about very often, so it’s absolutely amazing for us.

‘Employees said that it started conversations around a subject that might at times be quite sensitive to talk about. It also made the topic relaxed, and people felt able to share their own thoughts.’

Jessica, a Unit Manager for Bupa, says that Lift the Lid ‘normalises a conversation that is needed but kept hidden’.

‘The activities give staff the understanding, ability and confidence to respond in an appropriate and respectful manner, and to not react out of embarrassment and fear,’ she says. ‘It will help us to provide dignified care.’

Cultural shift
Staff at some Four Seasons Health Care homes have already made practical changes as a result of Lift the Lid.

Residents’ care plans have been reviewed to make sure their emotional and psychological wellbeing is being included. Discussions about sex and intimacy have been added to staff, resident and relatives meetings. ‘Do not disturb’ signs have also been introduced for some residents’ rooms.

‘Lift the Lid has created the foundation for a cultural shift that has enhanced residents’ experience of their care,’ said Reberta Rocella at Four Seasons. ‘We simply couldn’t praise this initiative more.’

Beverley hopes that Lift the Lid will lead to real and positive change across care homes.

‘We started a conversation about something that we were told is just not talked about, but we and many others have been talking about it ever since,’ she says.

‘We hope that sex, intimacy and relationships will no longer be seen only as a problem or a behaviour that needs to be “managed”, but as a human right to be respected and supported.’

Next steps
- Lift the Lid is available to purchase from our online shop – visit alzheimers.org.uk/shop
- For our Sex and intimate relationships (514) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- Your support allows us to innovate in these areas – for ideas, visit alzheimers.org.uk/fundraise or call 0330 333 0804 (local rate).
Musical Memories CD

Scarborough’s Singing for the Brain group recently launched our very own CD called Musical Memories. Over 50 people now attend weekly, and the group felt that our songs might be enjoyed by a wider audience.

In May 2018, the group recorded 20 of our most popular songs, and at a special concert in September, Musical Memories was launched to friends, families and local dignitaries.

Scarborough’s Singing for the Brain CD provides a wonderful opportunity for people to sing along, and is powerful testimony to the transforming effect that music can have on those living with dementia.

This wonderful achievement has only been possible with the determination of our lead volunteer, Gail Hartley, as well as support from Scarborough TEC college and Scarborough Cavaliers Rotary Club. Over 240 CDs have been sold to date, raising over £1,500 for the Society so far.

It would be wonderful if we could reach a wider audience – the CD would make a wonderful Christmas gift for a loved one!

You can buy a copy for £5, plus postage and packing, by calling our local Alzheimer’s Society on 01723 583998, or email scarborough@alzheimers.org.uk

Tim Kirkup, Singing for the Brain volunteer in North Yorkshire

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

Thank you to everyone who wrote in response to last issue’s letter from Peter Bailey about the possible effect of antibiotics that he had observed on his father’s symptoms of Alzheimer’s. We are sharing your varied experiences to make sure that these contribute to knowledge on this subject.
We want to hear about the hospital experiences of people affected by dementia in Wales for an inquiry run by the Welsh Assembly's Cross-Party Group on dementia. The aim is to improve hospital care as part of the Welsh Government’s Dementia Action Plan, and we also want to hear from health and social care professionals. You can submit evidence directly or through our online survey, in either English or Welsh. Visit alzheimers.org.uk/cpghospital or call Sophie Douglas on 029 2047 5580.

Welsh hospital care: Your experiences

We want to hear about the hospital experiences of people affected by dementia in Wales for an inquiry run by the Welsh Assembly’s Cross-Party Group on dementia. The aim is to improve hospital care as part of the Welsh Government’s Dementia Action Plan, and we also want to hear from health and social care professionals. You can submit evidence directly or through our online survey, in either English or Welsh. Visit alzheimers.org.uk/cpghospital or call Sophie Douglas on 029 2047 5580.

Winter flu vaccination

People with dementia are at increased risk of severe illness if they catch flu, and are being urged to have the winter flu vaccination. Also recommended for anyone aged over 65, vaccinations are available on the NHS from your GP surgery and many local pharmacies.
What's changed most since your diagnosis? I sometimes get lost or disorientated in places I know, and I find it very hard if I go somewhere I don't know. If I'm with friends or family, then I'm fine.

What would you take to your desert island? An album of 1980s music – that's my era – and Queen CDs. Also a Kindle, as I like adventure and crime books... and I don't mind a romance.

How has Alzheimer’s Society helped you? When I was first diagnosed, the Society helped with benefit claims and pointed me to local services. I was also introduced to a Side by Side volunteer. We meet every couple of weeks, have a chat and maybe go for a walk. It makes sure I get out, even if it’s raining.

What song or tune sums up your life so far? Don’t stop believin’ – Journey’s original version – because I can still do stuff, even with Alzheimer’s.

If you could go back in time, where would you go? Ages 16 to 21, when I used to go out every weekend with friends. We went on holidays together – quite a few Club 18–30 holidays! I still remember all of them. Although people have moved away, we’re still in touch on Facebook.

What is your most treasured possession? Family photos. My favourite is a black and white picture of Mum and Dad on Weymouth beach, from when they were ‘courting’.

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.
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

Get in touch
0300 222 5706
volunteers@alzheimers.org.uk

Alzheimer’s Society operates in England, Wales and Northern Ireland. Registered charity number 296645
Help at home

Crawley’s Forward Thinking group has a packed agenda each month. Drawing on their experiences of living with dementia to influence local authorities, health bodies and others – as well as raising awareness among the community – takes a lot of planning and reviewing.

We were delighted that they made time to try out daily living aids for our online shop, ranging from talking kitchen scales to a towel-off shampoo.

Talking time pal
The Talking time pal is a compact device that speaks the time when its button is pressed once, and the date if it’s pressed again. It can be worn around your neck or kept on a keychain.

Sandy said that, although the compartments on her dosette box are marked with the days of the week to tell her which pills to take, this doesn’t help if she can’t remember what day it is. However, she could check this simply by pressing the button on the Talking time pal.

The group were impressed with the price – £11.55 including VAT and only £9.63 without.

Talking kitchen scale and jug
The Talking kitchen scale and jug is designed to make measuring out quantities in the kitchen much easier. The jug has an easy grip handle and clear markings up to 1300ml, 44 fluid ounces and 2½ pints. It also has a notch beneath its spout to reduce spills. The scales speak the weight up to 5kg, in kilos and grams or in pounds and ounces.

Although she said her husband does most of the cooking, Vicky liked the secure feel of the handle when lifting the jug and thought the notch would be useful.

Peter was particularly glad of the option for the scales to give weight in pounds and ounces as well as in metric units.

Sensor light
The ‘Get up in the night’ sensor light is an LED strip that turns on in the dark when it detects movement nearby. When the motion stops, it goes off after 30 seconds.

Grahame and Beryl both said they could see this being very useful for when someone gets up in the night to use the bathroom. If placed beside a bed or on stairs, it would help them to orientate themselves and see where they are going.

Group members also thought the light was good value – £16.62 with VAT and £13.85 without.

Droplet
The Droplet intelligent hydration system reminds a person to drink regularly, using a tumbler or a mug with a handle. The cup base detects how often the tumbler or mug are used, and can be set to play messages that encourage you to take a drink.
Everyone could see the importance of preventing dehydration in this way, and Beryl said she’d definitely want one if she lived on her own. However, the volume of the messages was quieter than some in the group expected, even when set at its loudest.

That you can record your own messages was a mixed blessing for some – one group member reluctantly agreed that his wife’s voice would be especially effective for him!

**Towel-off shampoo**

Towel-off shampoo removes dirt and grease from your hair without needing any water – you simply rub it into your hair and then towel it off.

Peter, who gamely tried the shampoo out on the group’s behalf, said it certainly felt as though it worked, and that he’d use it if he wasn’t able to shower.

The shampoo comes in a handy 200ml bottle size, suitable for travel, and it is designed to work on all types of hair.

**Non-slip socks**

‘Amanda’ non-slip slipper socks, from the Able Label, are designed to be cosy as well as having a sole that grips to floor surfaces to make walking safer.

Although most people in the group said they had slippers, Sandy was really impressed when she put them on her hands to test the grip of their soles on the table surface.

The socks are Fair Isle knitted with a soft lining inside, and come in one size that fits most people.

Most of these products are exempt from VAT if bought for a person with dementia or other condition – if so, then the Talking time pal is £9.63, the Talking kitchen scale and jug £58.35, the ‘Get up in the night’ sensor light £13.85 and the Droplet intelligent hydration system £37.50. The Towel-off shampoo (£3.99) and ‘Amanda’ non-slip socks (£12.50) aren’t eligible for this kind of VAT relief.

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).

See p39 for a chance to win a Talking time pal.
In answer to your question (above), your friend may be aware of some rather complicated rules about deciding how much we need to pay for care.

When someone moves into a care home, the local authority usually looks at their income, savings and other assets – a financial assessment – to decide how much they’ll pay towards care costs. Most people contribute something, but how much depends on what this assessment says they have to pay.

Although you’re both free to give your savings to your daughter, if it looks like you did this to avoid your wife paying more towards her care, then it could cause problems.

It’s not about tax
Many people have heard about ‘gifting’ money for tax purposes, for example to pay less inheritance tax. However, tax rules are not the same as those governing how much people should pay towards their care.

Your own individual savings will not be included in the financial assessment for your wife’s care, but 50% of any joint savings will be treated as hers. If you were to make a gift of any of these savings to your daughter, the local authority may view it as a ‘deprivation of assets’.

Deprivation of assets
Deprivation of assets is when money that should have been included in a person’s financial assessment for care costs has been given to someone else. The local authority might still treat this amount as belonging to the person, even if it’s no longer in their possession.

The rules are complicated, but much will depend on the amounts involved and the reason you and your wife are considering giving money to your daughter.

Your wife won’t be expected to use all of her assets to pay for care. The rules about how much the financial assessment should ignore depend on whether you live in Wales, Northern Ireland or England.

Legal advice
It may be wise to seek legal advice before making decisions that could affect a financial assessment.

Solicitors for the Elderly could help find a solicitor near you with experience and knowledge of this area, and they don’t charge to do this. However, the solicitor would charge for a consultation.

To find a member of Solicitors for the Elderly near you, see www.sfe.legal or call 0844 567 6173 (call costs vary).

For our factsheets Paying for care and support in Northern Ireland (NI532), Paying for care and support in England (532) or Paying for care and support in Wales (W532), visit alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
What goes through your mind when we talk about Talking Point, our online community? Some people’s first thoughts might be ‘But I don’t use the internet’, ‘I don’t get on with technology’ or ‘It’s not for me’.

This is understandable if you don’t do many things online or if you’ve never been part of a similar community. Fear of venturing into the unknown could stop you from trying it out, or you might feel frustrated if things don’t work the way you expected them to.

Many Talking Point members have said they felt daunted at first by the idea of joining and taking part. However, it doesn’t take long for people to feel at home and they gain a huge amount of support and understanding – it’s a very welcoming place and there’s lots of help at hand if you need it.

Help at hand
You’ll find plenty of guidance and advice to help you use Talking Point. These include videos explaining how to use the different areas, as well as answers to new members’ commonly asked questions. These can be about how to do anything from finding your way around and posting your first message, to replying to someone else’s post.

We have a team of volunteers online to help with anything you might be struggling with. They’ve all been new to the community at one point, so they know what it’s like to be the ‘newbie’. If there’s something specific that you can’t get to grips with, you can also email the Talking Point team and they will help as best they can.

Take a look
To get a feel for what people are talking about and how it works, you may find it helpful to start by having a look around the community and the discussions taking place on it.

However you feel about technology, Talking Point is a place for you to share your experiences and ask questions, in a safe way with people who will 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 about a recently updated guide for anyone affected by a diagnosis of dementia.

Pocket guide

Harry Homan, a reader in Cornwall, says, “This is an excellent little book and much appreciated. It looks to be a very useful addition to our armoury in our struggles with Alzheimer’s.”

This is the second edition of a book recommended on Reading Well’s Books on Prescription for dementia, which means it will also be widely available from public libraries.

Calm and clear

Caroline likes the way the book is presented – it is clearly laid out, with short paragraphs and interspersed with helpful bullet points.

‘I especially like the bullet points in the chapter Getting Help,’ she says, ‘which describe the roles of professionals such as neurologists, Admiral Nurses and occupational therapists. In the Questions and Answers chapter, there is clear guidance in response to some frequently asked queries such as, “Who will pay for my mother’s care home?” and “How will I know if I am developing dementia?”

‘The authors make effective use of case studies in the chapter about treatment. There’s an example of how advice from a community nurse helped someone caring for a partner at home whose agitation was reduced by taking them out regularly for a short walk. Another case describes how someone with memory loss was helped to remember the names of plants he loved after a couple of months taking the drug donepezil.

‘There are also many practical tips, particularly in the chapter called Living with dementia. Each chapter concludes with a box of text containing key points, neatly summarising the discussion.’

Jo Weston, in Cambridgeshire, works for a charity that supports research into dementia.

She says, ‘Once I picked it up, I pretty much read it straight through. I thought the book packed in so much information about the various types of dementia, a topic I knew little about before reading.’

Caroline underlines the difference that getting the right information at the right time can make.

‘A diagnosis of dementia often leads to anguish and worry,’ she says. ‘For people diagnosed and their family and friends, this is the start of a new aspect to their lives and there can be a steep learning curve to find out more about Alzheimer’s disease and other kinds of dementia.’

Jo adds, ‘This book has provided me with a wealth of knowledge to understand so much more about what the diseases are, how they are diagnosed and managed, and what people can expect to have to deal with.’

The authors of our book this issue couldn’t come with a higher professional standing. Apart from Nori Graham being a Vice-President of the Society and of Alzheimer’s Disease International, she and James Warner both have years of experience as consultants in old age psychiatry.

Caroline Branney, who manages our Dementia Knowledge Centre, says, ‘This compact guide sets out to answer people’s questions in clear language without assuming an in-depth medical understanding.

‘So whether you want to know about the symptoms of dementia, more about how your brain works or to learn about treatments for dementia, this book will support you.’

Straight through

Jo Weston, in Cambridgeshire, works for a charity that supports research into dementia.

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The authors make effective use of case studies in the chapter about treatment. There’s an example of how advice from a community nurse helped someone caring for a partner at home whose agitation was reduced by taking them out regularly for a short walk. Another case describes how someone with memory loss was helped to remember the names of plants he loved after a couple of months taking the drug donepezil.

‘There are also many practical tips, particularly in the chapter called Living with dementia. Each chapter concludes with a box of text containing key points, neatly summarising the discussion.’

Jo agrees, ‘The style of the book is calm, clear and ultimately very digestible and understandable for non-medical readers. What an
Young-onset resources

This is my family
A book for younger children who have a parent with young-onset dementia. It tells the story of Jack, who is 13 and whose dad has been diagnosed. This is my family, by Barbara Chambers, Karen Harborow and Eddie Mort (Chambers and Harborow, 2017), 36 pages, £10.99, ISBN: 9780648013211.

Young-onset dementia
Alzheimer’s Society information about what young-onset dementia is, including the causes and symptoms, and how it is diagnosed and treated. Online information at alzheimers.org.uk/youngonsetdementia
For our factsheet What is young-onset dementia? (440) and booklet Young-onset dementia: Understanding your diagnosis (688), see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Dementia Diaries
Dementia Diaries enables people with dementia – many of whom have young-onset dementia – from across the UK to share audio diaries online. www.dementiadiaries.org

Wendy on audiobook
We featured Wendy Mitchell’s book about her experiences of living with young-onset dementia in our April/May 2018 magazine. It is also available as an audiobook, narrated by Rachel Atkins. Somebody I used to know, by Wendy Mitchell (Audible Studios for Bloomsbury, 2018), 8 hours 10 minutes, £13.12 (free with Audible trial) – see www.amazon.co.uk

Your turn
For the next issue, we invite you to read Will I still be me? by Christine Bryden (Jessica Kingsley, 2018), 144 pages, £12.99, ISBN: 9781785925559.
Let us know what you think about this book by 7 January 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 13 December quoting ‘Still’ for a chance to win one (see p39 for terms and conditions).
Celebrating together

‘We take Christmas to Dad and keep it simple. Not too many choices for dinner and a film that Dad would like. Last year we watched the new Dunkirk. Dad said it was boring and he would have preferred a cowboy film. We can’t win, so we don’t worry too much.’ Duggies-girl

“We always have a quiet lunch on Christmas Eve with my other half’s daughter. Last year I persuaded her to give me presents separately to be opened later, as too much excitement and a meal lead to problems. Television is a non-starter, as C won’t watch it much during the rest of the year. So the day itself has more music and less TV, as normal. I always make one wee special meal for the two of us with a German flavour, just to make her feel at home.’ nae sporran

“For her last two Christmas lunches, my Mum was asleep. I set up her tablet in front of her, set up a Skype call from my phone and joined the family at the table to eat. I could keep an eye on her, go into her if she woke, and if she woke quietly she could see and hear us.’ CaringDaughter

“This year two of my daughters and their families have decided they are coming to me on Christmas Day. I don’t have a big enough table for us all, but the two grandsons are going to have dinner in the sitting room with Grandpa. That will suit John nicely, as he likes his dinner on a tray nowadays.’ marionq

“My wife liked to do all the holiday cooking but couldn’t manage it now. We both like pasta so keep to simple pasta dishes, and make them different to the rest of the year by including smoked turkey and cheese in the ingredients. Of course, I indulge the famous dementia-related sweet tooth by joining my wife in eating as much as she likes in the way of chocolates, cake and biscuits instead of my usual form of trying to steer her towards a healthy diet.’ karaokePete

‘Perhaps the question is, “Does the person want to be included in the celebrations?” I think some people want to include a loved one in festivities as a way of comforting themselves, trying to make life as it was.” AliceA
Peoples with dementia often continue to find great meaning and enjoyment in music, even in the condition’s later stages.

Singing and playing music with others can be a powerful way to feel connected and express ourselves, including through a Singing for the Brain group, a choir or religious worship. Many people enjoy attending concerts, and many arts venues are trying to become dementia friendly. If you know a venue that could benefit from our guidance, refer them to alzheimers.org.uk/arts

When going to a performance isn’t possible, radio and TV – including online players like BBC iPlayer – provide many opportunities to enjoy music. If using complicated controls is difficult, simple ‘one-button’ radios and music players could help. As well as listening to music, people may like singing along to CDs and using songbooks.

Creating a playlist of favourite music can be done using many devices and streaming sites. However, Playlist for Life provides support that is specially designed for people affected by dementia – visit www.playlistforlife.org.uk

The BBC Music Memories site (musicmemories.bbcrewind.co.uk) offers around 1,800 clips of music from the last 100 years, which could help to explore what someone would like on their playlist.

Simple music players, one-button radios, CDs and songbooks are available in our online shop – see shop.alzheimers.org.uk or call 0300 124 0900 (local rate).

More ideas are included in our guide Taking part: activities for people with dementia, at a reduced price of £10 plus postage, also in our online shop.
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.’

Carer
Games and gadgets competition
P Skeete in Greater London won a Link and Think game and K Underhill in West Midlands won a Talking Time Pal. Answer: The first person to say ‘At the third stroke, it will be...’ for the UK’s speaking clock service in 1936 was Ethel Jane Cain, a telephonist.

Elf hat and T-shirt competition
D Holland in Buckinghamshire won an Elf hat with bell and Elf T-shirt, J Piper in Hampshire, C Heyworth in Lancashire, T Sansom in Nottinghamshire and R Howie in Dumfries and Galloway each won an Elf hat with bell. Answer: In the 2003 comedy film Elf, a boy grows up believing he’s an elf after inadvertently crawling into Santa’s sack on Christmas Eve.

Calendars competition
K Lilley in Essex won a 2019 Alzheimer’s Society calendar, C Owen in Cornwall a Memory calendar, and S Grimble in West Glamorgan a Stockings on the mantle advent calendar, while C Nott and D Davies in Hertfordshire, T Wakeley in Greater Glasgow, E Hutchinson in North Yorkshire and M Moss in Dorset won 2019 Alzheimer’s Society diaries. Answer: The 1985 TV series based on Sue Townsend’s book about a teenager with a love interest called Pandora Braithwaite was The secret diary of Adrian Mole.

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.

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

Talking Time Pal competition
We have Talking Time Pals for two lucky winners drawn from correct entries received by 19 December.

Q: The invention of the first machine that could record and play back sounds was claimed in 1877 by:

A. Henry Ossian Flipper.
B. Thomas Alva Edison.
C. Pyotr Ilyich Tchaikovsky.

Book giveaway
See p35 for a chance to win a copy of Will I still be me? by Christine Bryden.

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Pocket guide giveaway
The five readers who each won a copy of A pocket guide to understanding Alzheimer’s disease and other dementias, by James Warner and Nori Graham, were D Wrigley in Lincolnshire, H Homan in Cornwall, J Weston in Cambridgeshire, M Cheshire in Bedfordshire and G Alleyne in West Midlands.
Sale
up to 50% off

Sale starts 17 December!
We’ve got a wide selection of Christmas cards, diaries, calendars and gifts that are up to 50% off.

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