Check out our summer games!

Sunshine or rain, we have loads of exciting games for the whole family to enjoy.

We also have a great range of fun activities designed for people with dementia. These help to stimulate conversation and memories.

Visit shop.alzheimers.org.uk and if you need help with your order call our team on 0300 124 0900 (local rate).
Welcome

As we look forward to this year’s Memory Walk and push ahead with our campaign to end the dementia tax, here at the magazine we’re also looking at how we can improve what we do.

We want to develop the magazine so that it’s as useful as possible for everyone in the dementia movement and anyone affected by the condition.

Thanks to the people who took part in our April/May survey – over 2,000 of you – we have a lot more good information to base this on. We are very grateful to everyone who took time to do this. See p39 (behind the pull-out form) for details of the findings.

Of course, we still welcome your on-going feedback and ideas, including about a new name for the magazine (see p27), so keep on telling us what you think!

Danny Ratnaike, Magazine Editor
We would like to thank everyone who made this year’s Cupcake Day such a sweet success.

Over 23,000 of you signed up to support this Alzheimer’s Society event by baking or buying cupcakes on 15 June. We also caused a stir on social media by trending on Twitter during the day.

There was celebrity support from chefs Paul Hollywood and Rosemary Shrager, actress Suranne Jones, TV presenter Ruth Langsford and comedian Hugh Dennis.

Joy Watson (pictured), a Society ambassador living with Alzheimer’s in Salford, went far beyond baking and buying. She rode around her local community dressed as a cupcake in search of the best batch, raising awareness and smiles along the way.

We have counted £750,000 in funds raised so far from this year’s event, with more due to come in, which will take us above and beyond our target.

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End the dementia tax: Add your name

We are calling on all Alzheimer’s Society supporters to sign our online petition to end the injustice of families having to spend everything they have on dementia care.

The ‘dementia tax’ may have been a major issue during the general election campaign, but it is nothing new for people affected by dementia.

The national outrage over the dementia tax, a term we first used nearly 10 years ago, sends a thundering statement to politicians that dementia care is an issue that can no longer be ignored,’ said Rob Burley, Director of Campaigns and Partnerships at the Society.

‘Now we must unite to deliver a firm message to this new Westminster government that dementia must be a priority.’

The Society has welcomed the pledge for a consultation on social care, as outlined in the Queen’s Speech. However, this should not be used to delay workable solutions to the crisis in dementia care.

To fight this unfair system, where people with dementia in England don’t get free care on the NHS as they would if they had other conditions, we want our supporters to add their names to the petition and to share it with family and friends.

Sign the petition to end the dementia tax at alzheimers.org.uk/fixdementiacare

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New vascular dementia research

Alzheimer’s Society, the British Heart Foundation and Stroke Association are putting a combined £2.2 million into new research into vascular dementia.

The research includes a large study that will see how the memory and thinking of 2,000 people who have had a stroke change over two years.

By comparing stroke patients who develop vascular dementia with those who do not, researchers hope to understand its causes. This will help to improve how doctors identify and treat stroke-related dementia.

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Another amazing Cupcake Day

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We have counted £750,000 in funds raised so far from this year’s event, with more due to come in, which will take us above and beyond our target.
What’s good for your heart is generally good for your head – healthy eating and exercise are beneficial, whether or not you have dementia. So is getting out and about, and joining in with others. Too often, people affected by dementia feel isolated, which can lead to despair and depression.

Memory Walk this autumn provides a way to enjoy a fun, safe and healthy day out. Our wonderful volunteers make sure that everyone can have a good time. Of course, you can get sponsored to raise funds, and we need donations more than ever. Through last year’s Memory Walk, you enabled us to invest £10 million into prevention, care and a future cure for dementia. We’d like to do the same this year. Not only does it offer hope, but the support and advice that people need today would also be impossible to provide without your help.

Join me and thousands of others at one of our Memory Walk events – see memorywalk.org.uk or call 0300 330 5452 (local rate) to find events near you. You’ll feel better for it and you’ll be helping others at the same time.

Jeremy Hughes
Chief Executive Officer
Brain training: Does it work?

In July, newspaper headlines suggested that a ‘brain training’ app could slow dementia, though the evidence isn’t yet strong enough for this.

Brain training covers a range of activities from crosswords to computer games. Online brain training is a growing industry and many people use it to keep mentally active or improve their thinking skills.

The reports referred to findings from a study involving 42 people with memory problems that were very mild – not severe enough for a dementia diagnosis. Half of the people played a specially designed computer game for eight hours over four weeks, supervised by researchers. It involved remembering patterns, with correct answers awarded by virtual gold coins. The other half of participants only had their normal clinic visits.

People who played the game improved their memory scores. However, the study couldn’t show how long these benefits lasted, whether better test scores made a difference in everyday life, or whether this could help to reduce the risk of developing dementia.

James Pickett, Head of Research at Alzheimer’s Society, said, ‘We cannot extend the results of this study to apply to other brain training games, and we should be cautious about claims on some games that promise memory benefits, as these are often not backed up by evidence.’

A previous study of computer brain training that involved almost 7,000 people, funded by the Society, showed improvements in people’s reasoning and remembering of words, even six months on. However, more evidence is required to make a link between brain training and preventing dementia.

Dementia care research boost

Alzheimer’s Society has announced our biggest single investment ever in research to improve care for people with dementia.

After identifying the highest-priority research areas by consulting with over 500 people affected by dementia, we awarded £6 million to centres of excellence at the universities of Newcastle and Exeter and at University College London.

The research will look at improving care in advanced dementia, support after a diagnosis, independence at home and quality of life.

Dementia Friendly Awards 2017

Nominations are open for this year’s Dementia Friendly Awards to recognise those who have made a real difference to the lives of people with dementia.

Awards include Dementia Friendly Community of the Year, Dementia Friendly Organisation of the Year and Young Person’s Contribution of the Year.

Nominations close at midnight on 21 August for England and Wales, and midnight on 15 September for Northern Ireland.

The awards will be judged by people affected by dementia and others who work in the field.

The Northern Ireland awards ceremony will be on 28 November in Belfast, with the England and Wales awards presented in London on 29 November.

Nominate someone now at alzheimers.org.uk/dementiafriendlyawards

Carols at Christmas

Join us this December for our annual series of Carols at Christmas events, with 25 concerts this year across England, Wales and Northern Ireland.

The London concert takes place at Southwark Cathedral on 14 December, with a performance from award-winning choir Vasari Singers and an inspiring recital from a Singing for the Brain group, giving people living with dementia an opportunity to sing their favourite Christmas carols.

Celebrity supporters including Carey Mulligan, Ruth Langsford and Tony Robinson have attended our carol concerts in previous years.

Tickets will be available from 25 September, with all proceeds helping to transform the lives of people affected by dementia.
New-look lottery

The Big Win Weekly Lottery offers over £1,000-worth in 77 weekly prizes, with free entry into our quarterly super draws for a top prize of £8,000. Look out for our special TV advert promoting the new-look game.

Play to beat dementia at alzheimers.org.uk/lottery or by calling 01524 753238.

Readership survey results

Thank you to everyone who took part in our readership survey, which went out with our April/May issue. We had a very large number of responses – almost 2,200 – and it is clear that people get a lot from the magazine, and are also keen to find ways to give a lot back. The high number of responses means that we have some really valuable information to help to continue developing the magazine.

See p39 (behind the pull-out form) for details of the findings.

United at Pride

Alzheimer’s Society attended a number of lesbian, gay, bisexual and trans (LGBT) Pride events this summer, including Pride in London in June. As well as a high-profile presence on the London parade (pictured), we also provided information on our stand.

For our new booklet LGBT: Living with dementia (1511) and our updated factsheet Supporting a lesbian, gay, bisexual or trans person with dementia (480), see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

World Alzheimer’s Month

This September, World Alzheimer’s Month will provide a focus for us to challenge the stigma of dementia internationally.

Despite the World Health Organization (WHO) listing dementia in the top ten causes of death globally, most countries do not have a national strategy to address this.

The Society will share the stories of people affected by dementia to draw international attention and urge policy makers across the world to take action, and much of this will centre on World Alzheimer’s Day, 21 September.

WHO recently challenged international governments to recognise dementia as a public health priority through its global action plan. This recommends action and targets across seven areas – dementia awareness, risk reduction, diagnosis, care and treatment, support for carers and research.

Explore dementia risk

Alzheimer’s Society has developed an online resource showing how various factors can affect a person’s chance of developing dementia.

The interactive tool uses infographics to explore how factors such as age, genes, lifestyle choices and existing health conditions can have an impact on someone’s dementia risk.

Try the new tool at alzheimers.org.uk/dementiarisk
Take a stand

Believing that the opinions of people with dementia are often overlooked, Arthur Mars has embraced the opportunity to make himself heard. Gareth Bracken meets a man who is influencing the world around him.
A laughing Arthur Mars recalls his father’s advice when their family first moved to England in the early 1950s. ‘I remember being told, “We have to acclimatise – think British!”’ he says.

It’s fitting that we have arranged to meet at the classically British stately home and gardens of Hall Place, on the banks of the River Cray in Bexley, south-east London.

Arthur, 67, confirmed he had Alzheimer’s three years ago, but only after he and his wife took a stand with their GP over his right to a diagnosis. We take up his story many decades earlier, however, over 4,500 miles away.

**Early ambition**

In 1951, a three-year-old Arthur and his family moved to England from Guyana, at that time British Guiana, on the Caribbean coast of South America.

Arthur’s mother worked at the British Council and had been offered a position in London. His father, in the army, was also able to transfer.

The family, including Arthur’s three sisters, initially lived in Windsor, Berkshire. When Arthur’s father died in 1966, his mother couldn’t afford for all four children to stay in school, so Arthur started working aged 14.

Arthur got a job working on the signals at a local railway station. ‘I had to top up the paraffin lamps and trim the wicks, to make sure the signalman could give the red, orange or green signal,’ he says.

After nine months, Arthur took on more responsibility as a shunter, preparing trains in the goods yard. This required some knowledge of mechanical engineering, and he completed O-levels and A-levels in his own time, eventually becoming a signalman.

**Changing tracks**

Having been made redundant after 18 years on the railways, Arthur got a job with Kent County Council in the late 1980s.

‘They wanted someone with an engineering background to work on the highways, but I did all sorts as different departments amalgamated. They said, “You work on railways so you might as well do drainage too,”’ he laughs.

Arthur married his second wife, Sonia, in 2001. He had been married to his first wife for 18 years before her death.

‘I knew Sonia’s sister, who said, “I’ve got a nice girl I can introduce you to.” But she didn’t say it was her sister!’ he says.

Arthur worked for the council for over 20 years. It was in 2011 that he first noticed the signs of his dementia.

‘I was getting forgetful,’ he says. ‘I would forget minor things on the checklist at work. We always worked in pairs and the person working with me would cover up for me.’

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**Quick read**

Having been diagnosed with Alzheimer’s disease three years ago, Arthur Mars is determined to keep his brain as stimulated as possible.

Arthur and his wife had to take a stand with their GP over his right to a diagnosis.

He now attends a service user review panel, where people with dementia have their say on various pieces of work.

Arthur, who came to England from Guyana, would like more families from Caribbean communities to seek out services.
Taking a stand
Arthur took early retirement following medical advice from his employers, who were supportive. However, his GP was less understanding.

‘The doctor said, “Do you realise what it costs to have a referral to a mental health clinic? That affects my budget,”’ recalls Arthur.

Arthur and Sonia wrote a stern letter to the General Medical Council and the GP. They pointed out that, in putting budgetary concerns first, the doctor didn’t have his patient’s best interests at heart. Shortly afterwards they received the desired referral.

Over the following years, Arthur underwent numerous tests and an MRI brain scan. He describes it as a difficult time.

‘It was all upside down,’ he says.

‘This can’t be me’
In 2014, after seeing a psychiatrist at a memory clinic, Arthur was diagnosed with Alzheimer’s disease.

‘At first you’re in denial,’ he says. ‘This can’t be me – I remember most things. You can’t believe these things are happening to you.’

Arthur says taking medication has helped ‘even things out’, though he still has problems with communication.

‘I start a sentence well and then there’s a void – it won’t come. There’s a black space.’

He acknowledges the valuable support of occupational therapists following his diagnosis. Through them, Arthur has accessed activities and exercises to help improve his memory and communication skills, in addition to support for Sonia.

‘After we were set up with them, I did a cognitive stimulation therapy course and Sonia went on a carer’s course,’ he says. ‘That was when we realised that things will never be the same and that we had to make adjustments.

‘The occupational therapists said there are ways of keeping a quality of life. They told me, “We’ll do our best to stimulate your brain. We’ll get you involved in groups so you’ll keep on a steady flow and learn to accept the situation.”’

Through them, Arthur also joined a group for older people to share and discuss their experiences of dementia. ‘We all have dementia or are a carer, and can talk to each other and not feel afraid to speak our minds,’ he says.

Feeling empowered
Since last year, Arthur and Sonia have also been attending an Alzheimer’s Society service user review panel. These panels meet regularly so that people with dementia can help to shape different areas of national and local work (see p12).

At the first session that the couple attended, they gave feedback on design ideas for Living with dementia magazine.

‘They came along to ask our opinion,’ says Arthur. ‘Is it the right colours and presentation? The right order? Could it be tweaked a bit?

‘In another session we talked about an animation which helped youngsters understand and come to terms with a family member’s dementia.

‘We’ve also talked about how to make supermarkets more friendly for people with dementia.’

Arthur welcomes the opportunity to have a say on these matters.

‘It’s nice to have someone ask your opinion,’ he says. ‘You feel listened to and empowered. It gives us a voice.

‘Before, we felt decisions were being made and you were never consulted. No one ever said, “Where do you think we are going with this?” and took our views on board.

‘Most of the time people ignore those with Alzheimer’s, we’re on the fringes.

‘You walk into a bank – if you’ve got a question, there’s no
one to ask. You’re faced with a row of machines. If you’re not familiar with the sequence in which these things work, you can’t make a transaction. A little more thought and a bit of basic humanity and we could actually make the system work.’

Need to talk
Arthur is keen to underline the importance of seeing the person rather than their dementia. He is conscious of ways to include people whose dementia is more progressed, keeping everyone involved in conversations.

‘You see people at different stages at our sessions – one man thought he was in a doctor’s surgery. That’s fine with the rest of us, we’re all in a doctor’s surgery then. He was happy with that.’

Less positive for Arthur is the lack of diversity among those who attend the various sessions.

‘We’re in a cosmopolitan area but for every group or class we go to, we’re the only black people there,’ he says.

He puts this down to people in Caribbean communities finding it particularly difficult to accept that they have dementia. ‘They’re in denial. They refuse to face it.

‘It’s a cultural thing. Their elders have got this condition but rather than get treatment, people find every excuse to push it away into the cupboard.

‘The information is there but they won’t take advantage of services.’

Arthur certainly wants to accept any advice or support available in order to live well for as long as possible.

‘The occupational therapist tells me to think positively and wash all negative thoughts to one side,’ he says.

‘She tells me there’s no such thing as bad stimulation, so I’m staying involved.’

Next steps

- Join our campaigns to make sure that everyone with dementia can get a diagnosis and the right support – see alzheimers.org.uk/campaign

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

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

Members of our Cambridge service user review panel went undercover to see whether a department store is dementia friendly.

When department store John Lewis wanted feedback on how dementia friendly its Cambridge shop was, a local group of people with dementia agreed to do some mystery shopping.

Four members of our service user review panel in Cambridge visited the store approaching staff with queries that they thought would be useful to try out.

No fear
Jean asked to exchange a birthday card because she’d bought one with the wrong age on it, also explaining that she has dementia. Not only did she get it swapped, the staff member also helped her to select a new one.

‘I didn’t know what to expect, but she went completely out of her way to help me,’ says Jean.

‘She wasn’t one of these people who realised there was something wrong and froze. It can frighten them, they want to get rid of you – and quickly.

‘When I told her, it didn’t frighten her. She couldn’t have been any nicer.’

Ian wanted advice about buying a tin opener. The person he asked turned to a colleague for help, and Ian was very satisfied overall.

“She came back with another lady who sorted it,” he says.

“The staff were willing to give advice and you felt at your ease.’

Going further
David visited the toy department and asked for help in buying a small toy car. He felt the staff could have done more to support him.

“They weren’t sharp with me but they didn’t go any further than pointing me to the right place,” he says.

“I could tell they were busy but they could have taken me to that part of the department.’

The store’s signage was assessed by Dick, who wasn’t impressed.

“When you came out of the lift, you couldn’t see any signs at all. The sign was behind you as you stepped out!”

Spread the word
Many of the staff in John Lewis are Dementia Friends, which Jean believes is vital.

‘If staff aren’t trained, they don’t know how to act,’ she says.

The store’s management have the panel’s feedback from their visits, and David hopes the message will spread to other businesses in the area.

He says, ‘It’s nice to get it round that there is a problem, then other stores can think about what they can do.’
Having been shocked by his late father’s Alzheimer’s diagnosis, Graeme Burn was grateful for the Society’s involvement.

‘They were always at the end of the telephone to give us advice,’ he says.

‘They explained how it would impact him and how they could help.

‘Dad ended up in care and they were very supportive in that process of getting him into the right environment.

‘We were worried, but they helped us enormously.’

Humbling and uplifting
Wanting to give something back, retired teacher Graeme volunteered at last year’s Memory Walk, where thousands of people unite at events across the country to raise funds for Alzheimer’s Society.

He was a marshall at what he describes as the ‘spectacular cliff-top walk’ at South Shields.

Graeme directed and encouraged walkers as they passed him on the course.

‘It was very humbling to realise how many people are affected by dementia and how determined people were to walk and make their mark,’ he says.

‘It was also really uplifting to come across so many former students, colleagues and parents who were trying to make a difference.

‘Lots of people with dementia were on the walk, which was also great.’

Events such as Memory Walk wouldn’t be possible without the support of volunteers like Graeme, who is keen for others to get involved.

‘I would encourage people to volunteer,’ he says.

‘You get a load out of it. It’s a very positive and fun atmosphere, and also very humbling.’

Sharing a laugh
Graeme says that Memory Walk also gave him the confidence to volunteer for Side by Side.

‘I support a man with Alzheimer’s who recently lost his wife,’ he says.

‘We go out for a drive or go walking. We go to a museum or out for lunch.’

This Alzheimer’s Society service brings volunteers together with people who have dementia, helping them to continue getting out and about.

‘It takes the pressure off his family and gives him a different environment,’ says Graham. ‘It’s rewarding and really good fun.

‘He’s a lovely man who makes me laugh very much. He’s a smashing bloke.’

Volunteer at a Memory Walk near you – visit memorywalk.org.uk/volunteer or call 0300 330 5452.
School student David Byrne says that volunteering for Alzheimer’s Society was the ‘logical choice’ after we supported two family members.

‘My great-aunt and grandmother both experienced dementia in their latter years and I was thoroughly impressed with the wide-ranging support facilities offered by the Society during their time of need,’ he says.

‘I wanted to give back to the people who so generously helped our family, and effect positive change in the lives of those with a diagnosis.’

Recruiter

David, 17, is a volunteer recruiter in County Antrim, helping to promote opportunities for people to contribute their time and skills to the cause.

He has written articles about the work of current volunteers that have been published in a number of local newspapers. One piece recently helped to attract new volunteers to our Side by Side service, which supports people with dementia to keep doing the things they enjoy.

David, a student at St Louis Grammar School in Ballymena, has also been spreading the word at community events.

‘During a discussion at my local parish I talked through some of the opportunities, and a girl decided that she would love to get involved with the local activity group,’ he says.

Supported

David appreciates the support that Society staff have given him.

‘They take into consideration your expertise, talents, aspirations and passion, and craft a unique role which suits your schedule,’ he says.

‘The support I have received from my volunteering officer has been excellent. It’s wonderful to be able to meet with her on a regular basis to discuss and review our progress.

‘The educational opportunities afforded to volunteers have also impressed me thoroughly and I’m grateful to have the chance to learn so much about dementia.’

Development

David hopes to develop his volunteering further now that his exams are over.

‘I now feel that I have the confidence to offer my services in a more personal manner through something a little more hands-on,’ he says.

‘The Society has been incredibly flexible with my busy schedule as a student, and now that I have a little more free time it would be nice to offer my support in a different area.’

As he reflects on a positive first year with Alzheimer’s Society, David hopes that others his age will also look to get involved.

‘Volunteering is perhaps the most rewarding way to spend your time,’ he says.

‘I would love to encourage more, especially young, people to give their time to such a worthy cause.’

Find out about volunteering opportunities near you – visit alzheimers.org.uk/volunteer or call 0300 222 5706 (local rate).
Dementia became a prominent feature of the general election campaign, providing a focus for public debate about how our care is paid for and by whom.

We first used the term ‘dementia tax’ in 2008 to refer to the enormous injustice that exists in the care system in England. People with dementia are forced to spend hundreds of thousands of pounds on care, unlike those with other conditions who receive most of their care for free on the NHS. A large proportion of dementia care is social care – such as help with washing, dressing and eating – and this is means-tested.

This system is unequal and needs an overhaul. Regardless of the condition you have, you should have the same access to high quality and affordable care, and this includes people with dementia.

For a long time, successive governments have brushed this issue under the carpet. We have finally increased public awareness of the dementia tax and of how the current system is broken. Tens of thousands of people have signed the petition that we launched immediately after the election, calling on the government to address this injustice.

In an uncertain political landscape, we will be working hard with you to ensure that dementia remains at the top of the agenda, and that we see meaningful change. As the government consults on reform, we will put forward solutions for a new system that is fair and works for all people affected by dementia.

Sign our online petition to end the dementia tax at alzheimers.org.uk/fixdementiacare

Rob Burley, Director of Campaigns and Partnerships, calls on everyone to add their name to our campaign to end the unjust dementia tax.
In your area

Dementia Friendly Holywood

A project to make the Holywood area of Belfast dementia friendly launched officially with an event attended by the Mayor of Ards and North Down.

The launch of Dementia Friendly Holywood – a partnership between Alzheimer’s Society, Dementia NI and Radius Housing – featured people with dementia speaking about their experiences.

The project states that everyone living and working in Holywood has a responsibility to ensure that people with dementia feel understood, valued and empowered to contribute to their local community.

In its opening months, Dementia Friendly Holywood has met with the Holywood Chamber of Commerce to provide local businesses information about its plans. It has also held memory cafés and organised a carer support coffee morning.

Marathon run-up

A family of fundraisers have the Birmingham International Marathon in their sights as part of a string of challenges that they are taking on in support of the Society.

Members of the Bansal family – Jay and Mohni with daughter Immy and son Rajinder – will have completed over 50 events throughout 2017, from 5-kilometer runs to 100-mile bike rides. Rajinder will run the 26.2-mile Birmingham event in October.

They hope to raise more than £2,000 in memory of Kundan Singh Bahra, who lived with dementia in his later years.

The family said, ‘Our father and grandfather truly did mean the world to us and so it’s quite hard to get on with day-to-day life without him.

‘There is a lot of stigma and specific support required in our community to help people with dementia, so we want to raise money and awareness of this important work.’

To donate, visit www.justgiving.com/ksbahra

Society stalwart receives MBE

Sue Phelps, at Alzheimer’s Society Cymru, has been awarded an MBE for services to dementia in Wales.

Sue, who has worked as Operations Director for Wales since 2012, has championed the rights of people with dementia throughout her 20 years with us, working tirelessly to ensure that services meet their needs.

She said, ‘I am proud to play my part in raising much-needed awareness of dementia and doing as much as I can to ensure services and support are available, when needed, for people living with dementia right across the country.

‘I am still as passionate about the cause as when I first joined.’

LGBT memory café

A new memory café in London is to support lesbian, gay, bisexual and trans (LGBT) people with dementia and carers.

The Rainbow Memory Café, which is being launched in October by LGBT charity Opening Doors London with funding from the Big Lottery Fund, will offer peer support, activities and information.

‘This is an exciting opportunity to offer LGBT people a welcoming place to get support and information about dementia, have some fun and most importantly be themselves with others who are also LGBT,’ said café co-ordinator Sally Knocker.

Anyone interested in attending the café can contact Sally at sally.knocker@openingdoorslondon.org.uk or phone 020 7239 0400.
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
New outlook

Quick read

Louise Wade cares for her husband Simon, 49, who was diagnosed with young-onset Alzheimer’s disease in early 2016.

They decided to be as open as possible about his dementia, though this has had an impact on their children and some friendships.

Louise and Simon take part in a local young-onset dementia group, for which she also volunteers.

Louise takes strength from what the family has come through so far, and she tries to keep busy and remain hopeful.
Since her husband’s dementia diagnosis in his late 40s, Louise Wade’s family has had to fight to get where they are. Gareth Bracken meets a carer facing up to a new outlook.

After noticing problems with her husband’s memory and his attempts to compensate, Louise Wade urged him to go for tests.

‘I could see there was something wrong,’ says Louise, 47. ‘Simon would invent stories about his whereabouts because he couldn’t remember where he had actually been.

‘I knew in my heart it was Alzheimer’s. I recognised the behaviour and forgetfulness from his mum, who also had young-onset dementia.’

Simon was diagnosed with young-onset Alzheimer’s in January of last year, aged 48.

‘It was like a bomb going off, an explosion and then silence,’ says Louise. ‘We didn’t know what to do.

‘I broke down – I felt very cheated.

‘My grandpa also had Alzheimer’s. Sometimes I think, “What have we done wrong?”’

Louise, who lives in Sheffield, is grateful for the support the family received from the NHS in those early days.

‘The community team came out within six weeks of diagnosis. They were excellent and helped me to get help,’ she says.

‘A lot depends on your GP. Ours is excellent but other people who only live a few miles away have had no guidance, which is shocking.’

Feeling robbed

Louise and Simon were together as teenagers until their early 20s, when they parted but stayed friends. They lost touch until Louise moved back to Sheffield in early 1998, before a chance meeting led to them rekindling their relationship the following year.

‘It was only our fifth wedding anniversary in June – that’s why I feel robbed,’ says Louise.

‘To make matters worse, she fractured her back not long before Simon’s diagnosis.

‘It was a very dark and difficult time,’ she says.

‘Simon was a decorator before his dementia forced him to stop work, while Louise’s career has also been curtailed.

‘I went from running my own business to working part time in a bank. Then I gave up work altogether, partly because of my back and partly because of Simon’s dementia,’ she says.

‘I was always the chief breadwinner, then all of a sudden you can’t do that. It was pretty scary to give up that role for the first time in years. It took a lot of adjusting to.

‘We’re treating this as our retirement,’ she says. ‘We’re lucky we like each other!’

Telling the kids

The couple have a 13-year-old son, Mikey, as well as twin 19-year-old girls from Louise’s previous relationship.

‘At first Simon didn’t want to tell them it was Alzheimer’s, but then we started to talk more openly and answer their questions honestly,’ says Louise.

‘Mikey worries he will get it. He has asked me about that, and about what will happen to his dad.’

‘Having Alzheimer’s has caused Simon to lose some of his inhibitions, which has affected his relationship with his son.

‘Louise says, ‘If Simon bursts into a dance on the shop escalators or sings in the street, I go with it, but Mikey would be embarrassed.’

Last on the list

Simon’s dementia has also led to the couple losing touch with previously close friends.

‘There are some who we very rarely see – we’re last on the list,’ says Louise. ‘It really shows you who your friends are and aren’t.

‘I found it really upsetting and hurtful at first. Simon tried to excuse it, but when I could see him upset I was so angry. It was killing me inside.

‘Simon’s best friend said he couldn’t come into the house because he had to rush off to Leeds, then my dad saw him in the local pub. It’s disgusting – don’t lie to Simon.

‘On the upside, people who were just friends that we saw occasionally have now become good friends.

‘We could go two ways – sit on the sofa and cry or throw ourselves into it and make new friends.’

Louise strives to keep the family as busy as possible, as a way of coping.

‘We’ve always got something on because if I stop, I get sad and hit meltdown,’ she says.

‘That’s when I have a good cry to my mum, brush myself off and tell myself to get on with it.

‘I think I manage pretty well overall.’
**50–64 Project**  
The couple regularly attend various groups, including the local 50–64 Project for people with young-onset dementia and their carers, run by Alzheimer’s Society. The project has developed a network of peer support and a programme of social activities in Sheffield. Louise is heavily involved as a volunteer, using her local connections to help organise a Christmas carol concert and craft sessions at a local café, led by experts.

‘I know people in the area and Simon has lived here for most of his life. I’m cheeky – I just ask people for their help. Nobody’s ever said no yet,’ she says.

‘We have friends with local shops who want to become Dementia Friends, sell wristbands and have money boxes.

‘People will say to me, “I’ve come up with an idea.” That’s because we’ve not hidden the dementia away and have been really open about it.’

Louise and the other 50–64 Project carers have also formed a group on the messaging app WhatsApp to share advice and support.

‘I think people sometimes have romantic notions of people in 1940s gear singing songs in a care home, but we have to conduct normal family life and go through all the struggles that come with it,’ she says.

**What’s normal?**
Louise has shared her story on BBC Radio Sheffield and has no qualms about being so open about her experiences.

‘I don’t want to be ashamed. Everyone’s different – what’s normal?’ she says.

‘I hope to give other people hope. See what’s out there. I’m not saying you can do it in the first week when it’s very dark, but once the shock has settled.’

Although she keeps herself and Simon active and involved, Louise remains aware of tough times ahead.

‘I’m really worried about the future. I find it very hard,’ she says.

‘I try and kid myself that the plans we had will move forward, but in my heart I know we’ll be bloody lucky if that happens.

‘I just hope that we’re as we are for as long as we can be. But I can see where it’s going from the rest of the 50–64 Project group.’

Louise can at least take some strength from her family having even made it this far.

‘It’s taken some fighting to get where we are today but we’ve come through it,’ she says.

“We could go two ways – sit on the sofa and cry or throw ourselves into it and make new friends.”

Next steps

- For our Young-onset dementia: Understanding your diagnosis (688) booklet see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

- Become a Dementia Friend or Dementia Friends Champion – see dementiafriends.org.uk

- For more about dementia-friendly communities, visit alzheimers.org.uk/dementiafriendlycommunities
A new study is looking for participants to see how technology could help people living with dementia to avoid crisis situations. **Gareth Bracken** hears from the researchers and people already taking part.

**People with dementia and carers in Surrey and north-east Hampshire have a new opportunity to find out how technology could help them remain safe and well in their own homes.**

A study called Technology Integrated Health Management (TIHM) for dementia, supported by Alzheimer’s Society and funded by the Department of Health, is being led by Surrey and Borders Partnership NHS Foundation Trust.

By trying out the latest technology in their everyday lives, people with dementia will help researchers discover more about avoiding crisis situations and unnecessary stays in hospital.

**Help when needed**

The researchers install a number of small devices in a person’s home, allowing professionals to keep an eye on their health and wellbeing as changes take place.

If it looks like the person with dementia might need some support, the monitoring team can contact the carer or arrange an Alzheimer’s Society visit. If there is an emergency, they can also contact the right services.

Dr Ramin Nilforooshan, a Surrey and Borders consultant psychiatrist involved in designing the study, says, ‘In the current system, a person with dementia is referred by their GP or family member to a clinic and then gets an assessment and medication, but there isn’t much of a follow up.

‘People with dementia are usually stable for a time, but they might end up in hospital in crisis at some point, which is stressful for them and their family.

‘We thought, rather than waiting for these crises to happen, let’s see if we can predict them so that we can step in early to offer support.’

**Reassuring**

The full study – involving several hundred people across Surrey and north-east Hampshire – begins later this year, but 14 people

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**Quick read**

A study is seeking people with dementia in Surrey and north-east Hampshire to find out how technology can keep them safe and well at home.

Researchers use small devices around the home to keep an eye on a person’s health and wellbeing.

Marion Edwards, whose husband John has Alzheimer’s, finds it reassuring to know that the right people will be contacted when problems are picked up.

The doctor behind the study hopes its findings will dramatically improve support for people affected by dementia.
have been testing the technology before then.

These include Marion Edwards and her husband John, who was diagnosed with Alzheimer’s in July 2015.

Twice a day, they take readings for John’s body temperature, blood pressure and blood oxygen, and use special scales to check his weight and hydration. This information goes straight to someone who can interpret it, without the need for a clinic or home visit.

John carries a GPS tracker and wears a watch that can detect if he has had a fall, while sensors monitor his movements around the house. The couple also answer basic daily questions about John’s wellbeing on a touchscreen device.

‘It’s very reassuring. You feel that somebody’s there if there is a problem,’ says Marion.

On one occasion John’s blood pressure was low and he was told by the monitoring team to visit the GP.

‘You’re not worrying the whole time that something you don’t really know about is happening in his body,’ says Marion. ‘You are supported mentally and medically.’

### Not intrusive

Clinicians monitor John’s data 12 hours a day, while an emergency line is open at all hours in case of more serious incidents.

‘Marion can go out without worrying about me. She knows they’ll ring up if it’s necessary,’ says John. ‘It’s really just giving her a break. If I know that she’s happy, it makes it a lot easier.’

Phil and June Bell are also trying out the technology for the study. June, who has dementia, has been to hospital a number of times in the past six months.

‘We don’t want to do that,’ says Phil. ‘If there’s a way of avoiding that, it’s got to be a benefit to us.’

Neither couple has found the technology to be intrusive.

‘It’s more reassuring than intrusive,’ says Phil. ‘We find it a really good way of being able to stay at home for as long as possible.’

### Better care

Dr Nilforooshan hopes that the results of the study will help them to improve dementia care. The current system of scheduled appointments means that problems aren’t always picked up quickly and so are more likely to escalate. This can lead to unnecessary stays in hospital, which carry their own risks.

‘It requires a change in the way the NHS works,’ he says.

Recruitment for the full study is open and Francesca Markland, managing the project for Alzheimer’s Society, says that people who get involved will be supporting a valuable piece of work.

‘This could help to revolutionise healthcare management for people living with dementia and their carers,’ she says. ‘We see technology becoming more and more prominent and the data from this study will be so important to generations to come.’

Marion says that she and John feel ‘very privileged’ to be taking part in TIHM for dementia.

‘It’s quite exciting – feeling that you’re in at the ground level of developing something which could be really useful.’
At the Dementia Positive Living Group in Suffolk, people with dementia and carers have been getting advice and support to help come to terms with a diagnosis, manage symptoms and make the most of life.

‘I kept hearing of people getting diagnosed but not knowing where to go,’ says the group’s organiser Gill Austin, a nurse at St Nicholas Hospice Care in Bury St Edmunds. ‘They had no signposting to further support, so were left floundering.

‘I realised we needed to do more on dementia, so I tried to think of ways to fill in the gaps. We already had a group for life-limiting conditions, so we decided to make that dementia specific.’

Working in hospice care, it was obvious to Gill that people living with a terminal condition need support so that they can plan ahead. However, she also knew it would be important to involve other organisations.

Gill teamed up with Maggie Woodhouse – a dementia specialist at West Suffolk Hospital – and the local Memory Assessment Team to deliver a four-week course to four couples where one partner had dementia. ‘We’re from different organisations, so bring different perspectives,’ says Maggie.

Like a rock pool

The three-hour sessions took place in the welcoming setting of Nowton Court Village, a supported living and respite care provider in Bury St Edmunds.

David Newton attended with his wife Janet, 78, who has vascular dementia and Alzheimer’s. He values the overview of available services that the programme provided. ‘It’s life-changing when your partner is diagnosed,’ he says. ‘I find it very difficult to get an overall picture of support. The whole system seems to be so fragmented.

‘It’s like a rock pool, you pick up a stone and there’s a hive of activity underneath it.’

Each session focused on a different area, such as dementia symptoms and their everyday impact, communicating and coping with difficult situations, and financial, legal and care planning. One session looked at how to access services, covering
means testing, personal budgets and end of life care. Guest speakers – including a solicitor, care home provider and someone from social services – answered people’s questions about their specific circumstances.

Out on a limb
John Riddick’s wife Carol, now 77, was diagnosed with Alzheimer’s in 2014. He says the group has been ‘full of useful information’.

‘We hadn’t had contact with any organisations apart from right at the start, when Carol attended a series of cognitive group therapy sessions,’ he says. ‘We felt a bit out on a limb and were struggling a bit. I needed some sort of help.’

‘There’s nothing like meeting people in a similar situation. I needed contact from other people to help me form in my mind how I should be acting as a carer, and to learn what other carers did.

‘That has proved to be the case and the group has met all of my expectations. I think Carol finds it useful too, particularly meeting other people.’

John says the couples could keep in touch beyond the four weeks. ‘We’ll probably all meet again – I shall suggest it.’

Jenny Gough, whose 81-year old husband Tony was diagnosed with mixed dementia earlier this year, is also pleased to have taken part.

‘I’ve found it very informative. I’ve got so much information I can’t cope!’ she jokes.

Tony has enjoyed the sessions too. ‘It’s been very good,’ he says.

‘They’re quite an interesting bunch of people, a nice bunch. They all support each other.’

He feels better about the future now, adding, ‘It’s nice to know I’m not the only one.’

Making bonds
With only eight members, the group has a relaxed and friendly feel. Anne Hayward’s husband John, 78, was diagnosed with dementia in 2015, and she says he copes better in this environment.

‘We find it very good – it isn’t too big,’ she says.

‘John isn’t very social at the moment, he doesn’t like mixing. In large groups, he misses a lot of what’s going on because he doesn’t hear very well.’

They also appreciated the subjects that the course covered. ‘People have told us about things we didn’t even know about,’ says Anne.

‘I think John is quite glad he came along – he has found the information useful.’

David describes the sessions as ‘very social’, while John Riddick says the group members have ‘very definitely’ come together over the weeks.

For organiser Maggie, this has been one of the great successes of the programme ‘They’ve gelled as a group and made ongoing relationships,’ she says.

Gill and Maggie are already planning another Dementia Positive Living Group for a new set of couples later this year.

As the final session comes to an end, a grateful Jenny concludes, ‘Considering it’s the first one, they’ve done very well.’

Next steps

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

- The dementia guide is for anyone recently diagnosed with dementia – see alzheimers.org.uk/dementiaguide or call 0300 303 5933.

- Volunteer to help provide support and advice to people in your area – visit alzheimers.org.uk/volunteer or call 0300 222 5706.
Mum’s Alzheimer’s diagnosis was five years ago now, so my children have had many years of the ‘pep talk’ before visits: ‘Please don’t interrupt and make sure you look at Granny when you’re speaking... don’t mumble, otherwise she can’t hear... if she’s not chatting or doing something, she’ll wander off and become disinterested. It’s really important to me that she enjoys our visits!’

It is repetitive and exhausting. My children don’t understand why Granny remembers some things and not others, with their patience limited and their ability to think of anyone else before themselves non-existent. I try my hardest.

‘Ooh, who are you?’ is Mum’s usual cheery greeting (with a cheeky grin). I have lost the ability to work out whether she is joking or not anymore. Sometimes she clearly knows exactly who I am and other times I catch her staring intently, searching for my name. Not allowing myself to become upset, I make it easier by telling her straight away, giving her a big hug and kiss, putting everyone at ease immediately.

As one child slumps onto the sofa in silence, the other begins fiddling with his fidget spinner from his pocket. I try to carry on the conversation, but am battling with my real thoughts: ‘Why can’t they just be polite and sociable for one hour. Is it really too much to ask?’

Then something unexpected happened. Mum leans in to see what my son is fiddling with and they engage in this wonderfully lengthy conversation. She becomes mesmerised by the different coloured spinners, taking it in turns, taking them apart, spinning them in different directions, stacking them up while nattering away to one another for ages.

I was totally shocked that this kid’s toy craze had suddenly become something so very fascinating to my mum. It had become in that magical moment – the perfect visual and tactile thing for them both to share together.

I hope they will enjoy this special time together with the fidget spinners – almost as much as I will enjoy watching them together!

Chloe, Somerset

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

A fidget spinner
The Society’s magazine began years ago as a newsletter for carers, called Share. It was joined by a second newsletter for people with dementia – named Living with dementia – before the two were merged into a single magazine in September 2007.

The magazine has changed hugely since then, both how it looks and the range of people who read it. The results of our survey (see p39, behind the pull-out form) have told us that the magazine is extremely valuable for many people. It’s given us good ideas for new content and underlined how else it might be distributed.

As well as this, we want a name that tells everyone in the dementia movement and anyone affected by the condition that this magazine is for them.

We’re collecting ideas for a new name at the moment, and we’ll be testing these with groups of supporters and people affected by dementia in the coming months.

If you have any ideas for a new name for the magazine, we would love to hear from you – email magazine@alzheimers.org.uk or call 020 7264 2667.

What’s in a name?

Tell us your ideas for a new name for our magazine.

Call our trained advisers on 0300 222 1122 or email helpline@alzheimers.org.uk or alzheimers.org.uk

Talk to us. We’re here for you.

If you have questions or concerns about dementia, our National Dementia Helpline is here to provide information and support – seven days a week.
Diana Carmichael
Flintshire, north Wales, aged 80 with Alzheimer’s disease

What’s changed most since your diagnosis?
I am now more aware of the problems that other people face and I feel able to help them adjust to their situations. I try to lift them, to let them see how they can come out of it.

What would you take to your desert island?
A photo of the family, plus a contact in the form of a mobile phone! Also, a necklace that one of my granddaughters made for me, from pieces of wood.

How has Alzheimer’s Society helped you?
Because of the volunteers, activities and staff, I can help other people to have a more positive attitude to their lives.

What song or tune sums up your life so far?
My mum’s hymn from when I was little – O gentle presence, peace, joy and power.

What single thing would improve your quality of life?
My quality of life is always good now, I wake up happy and I go to bed happy!

What is your most treasured possession?
My husband Clive and our precious family. We have five children and 10 grandchildren, and we’re always there for each other.

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.

A slight disruption to Ma’s routine – someone in the house to carry out a repair – and the faithful note advising her to take her medication becomes dislodged. She then can’t remember whether she has taken the pills or not, so takes a second dose. This makes her very sick and means an unwelcome trip to A&E to make sure she’s OK. Apparently, a double dose of one medication wouldn’t always cause a problem. However, she doubled up on two – one of which was her Alzheimer’s medication – and the combination made her unwell.

Happily, she does not have to spend too long in the hospital, something we’ve always dreaded. She is now back home fully recovered, probably without much memory of her ordeal.

Ma resumes the roles that she feels most at home with, caring for other family members and ironing everything she can lay her hands on. Delicates need to be hidden, as the setting remains resolutely on hot. Neatly ironed items can be found in all corners of the house, including a vast array of unpaired socks.

Our daughter plans to celebrate her birthday with a trip up north to be with Ma, giving Ma another pleasure – buying a birthday card. We are hoping that Ma will return to us for a holiday in August and be reunited with her old room, plus another opportunity to complain about the lack of doors in our open plan kitchen!

Dilly, a daughter-in-law
(continued next issue)
Are you looking for information, advice or support?

If you or someone you know has questions or concerns about dementia, we are here for you. Turn to us for a range of expert information and support for anyone affected by or worried about dementia.

Talk to us
Our National Dementia Helpline can provide information, support and guidance.
Call 0300 222 1 122 (national rate or less) 9am–8pm Monday to Wednesday, 9am–5pm Thursday and Friday, 10am–4pm at weekends or email helpline@alzheimers.org.uk for Live Online Advice and other information.

Find the information you need
Our wide range of publications provides information about all aspects of dementia and dementia care. See alzheimers.org.uk/publications

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

Talk to others
Talking Point is our online community for anyone affected by dementia 24 hours a day, 365 days a year. Visit alzheimers.org.uk/talkingpoint

‘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

alzheimers.org.uk
alzheimers.org.uk/facebook
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Remember together

On day eight of Wimbledon, and only a handful of stops away from the tournament on south London’s trams, a lively activity group at Merton Dementia Hub took tennis as one of its themes.

We joined them with some new reminiscence cards from our online shop to see what they thought of these, alongside everything else they were doing.

Timeslide albums

We took four ‘albums’ of Timeslide reminiscence cards from Active Minds to the group – Animal, Home, Loves and Holiday. Each card has a large picture from the 1950s to the 1970s on its front, with points and questions on the back to prompt conversation about memories.

Seeing a picture of a woman ironing in the 1960s on a card from the Home album, Jim said, ‘I remember the iron being plugged into a light fitting in the ceiling because there wasn’t a power supply.’

Jim added that there was an opening in the back of the iron where you placed a piece of metal you had heated on the fire, and Marie recalled using tongs to do this.

A photo of a fridge on another card brought back memories of when it was usual to have a larder, and drew Rick and Mary into the exchange. Rick talked about starting to remove the cold stone shelf in their new home’s larder after getting their first fridge. By the time he realised that the same piece of stone continued into the neighbour’s larder, the damage had already been done!

Overall, group members said the pictures were clear and interesting, and the text easy to read and understand. The cards started all kinds of discussion, and could be a great way to share memories between generations. The compact packaging of each album also means they are portable and simple to store.
Weekly Sparkle
The group receives a new issue of the Weekly Sparkle for each time they meet, produced by the same organisation as the Daily Sparkle newspaper (pictured). Its 10 pages of stories, including events ‘on this day’ from previous years, are designed to stimulate memories and conversation.

People enjoyed reading the articles throughout the session, and the group came together at the end to go through the five quizzes at the back – which Peter joked gave everyone time to cheat if they were struggling!

Rex led a number of people who enthusiastically shared their answers to questions about word pairings. A quiz about bands from the 1960s also prompted people to recall each group’s most famous hits.

Wimbledon theme
A range of tennis memorabilia was to hand throughout the session. Although there could be no space for a tennis court, Harry and Sarah were among those to play a few rounds of ping-pong, taking advantage of the specially set up table.

Lena, who facilitated the group, had also organised a Wimbledon-themed quiz. After the Weekly Sparkle quizzes, everyone went through questions not only about previous champions and famous matches, but about tennis-related books, films and TV series.

Altogether, the range of activities and the warm, welcoming environment meant an enjoyable time for all.

However, as Peter observed, ‘The activities are great, but the real point is that everyone ends up talking to and supporting each other.’

Active Minds Timeslide albums are available from our online shop for £11.99 each – visit shop.alzheimers.org.uk or call 0300 124 0900 (local rate).

A subscription to the Daily Sparkle or Weekly Sparkle costs £59 per month, including a monthly singalong CD and ‘carers’ notes’ for each issue. See www.dailysparkle.co.uk or call 0800 228 9698 (free).
Hiding medicine

If someone isn’t taking medication that they need to keep well, concealing it in their food or drink can seem an easy solution. However, this raises some questions that are important to deal with.

Why is it happening?
Is your husband refusing to take these tablets because they are difficult to swallow? Has he been put off by an unpleasant taste or side effect? If he has taken them before without difficulty, could there be another reason behind him spitting them out now? Sometimes you can work out what is going on by talking to the person about it.

There may be situations where he is more comfortable taking the pills than others. This might be as simple as when he is sitting in a familiar chair, or if a particular person is there.

You can ask the GP whether this medication comes in a liquid or another form that is easier to swallow. Sometimes another brand of pill can taste different while being just as effective.

Is it their choice?
Disguising medicine means that the person believes they are not taking it when in fact they are. We all have the right to consent to medication – if someone doesn’t know they are receiving it, they can’t have given informed consent.

Your husband may or may not be able to decide for himself whether to take these tablets. If he can decide, then it is his choice to make. If he can’t make this decision himself, even with your or others’ support, then a decision may be made on his behalf if it is in his best interests. You should get advice from a health professional about this.

If taking the medicine is the best thing for your husband, find a way to give it to him that affects his rights in the smallest way possible, and try to ensure that this is recorded in his care plan. Talk to the GP, or whoever prescribed it, and anyone else involved in caring for him. If there is no other way, then hiding it in his food or drink could be the solution.

Will it affect the medicine?
Hiding medicine in food or drink – or even simply crushing a tablet – may affect how your husband’s body absorbs it, and so how effective it is. This is another reason why you should check with a health professional before doing this.

For our Making decisions and managing difficult situations (484) factsheet, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
Keeping clean

It can be challenging to support someone with dementia who is reluctant to bathe or wash. As their condition progresses, the person will need more help to maintain their personal hygiene. Washing and bathing is a private and intimate activity for most of us, so it can be difficult to adjust to this.

Needing help with everyday tasks can be very hard to accept, for both the person with dementia and their carer. However, it’s important to remember that you are not alone.

Sharing online

Many people share experiences and hands-on advice through our online community, Talking Point. Whatever challenge you are facing, the chances are there will be someone who has been in a similar situation.

Some of the specific areas that Talking Point members have supported each other with include how to respect someone’s choices while helping them to keep their dignity, encouraging someone to accept help, and maintaining a person’s independence.

Carers’ tips

Suggestions to make things easier have included getting things ready in the bathroom before going there with the person, talking them through the steps as they are washing, and involving them in decisions as much as possible.

Other tips range from making sure the room and water temperatures are comfortable, to helping the person hold the showerhead themselves.

After washing, wrapping a towel around the person followed by a dressing gown could help them to feel comfortable, and they may be able to dress more easily if you hold out their clothes for them as they do it.

Less alone

There are forums on Talking Point for challenges that can arise in all stages of dementia. By sharing what is happening and how it affects them, many people feel less alone and more able to deal with things.

For our Washing and bathing (504) factsheet, visit alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
Sarah Zoutewelle-Morris is an expert in visual arts, and she has applied her skills to her work as an artist in health care for many years.

Caroline Branney, who manages our Dementia Knowledge Centre, says, ‘This imaginative book is designed to be used by those who may have limited experience of creative activities, including family members, as well as practitioners working with people who have dementia.

‘Chocolate rain can be dipped into, though the author recommends reading the brief chapter called “Taking a step towards their world” first. This encourages us to “have a go”, be open-minded and take time to be creative in our thinking. It also reminds us to recognise the potential of a person with dementia rather than starting with perceived limitations.’

Lynne Pierce, in Gloucestershire, says, ‘It could be an extremely valuable and user-friendly book for professional activity providers and family members. It covers many aspects of practical involvement and engaging activities.’

She adds that it encourages creativity from everyone involved – people with dementia and carers.

Abida Parveen in West Midlands is just as enthusiastic. ‘I am really learning so much from it. I particularly like how it shows how to put these activities and ideas into practice in a care home setting.’

Practical and meaningful
The book groups and cross-references activities – from holding objects, adapting games or making window decorations and hanging mobiles to activities based on a person’s former profession – according to specific needs and goals.

‘For example,’ says Caroline, ‘under “individual activities” it provides ideas for a person who can speak but cannot read or for someone who is bedridden. Descriptions such as “simple”, “no cost” and “quiet” – together with lots of attractive illustrations, photographs and bullet points – help you to pick the right activity quickly.’

Lynne says, ‘It breaks down complexities of a project into “do-able” tasks that are enjoyable, rewarding and fun. It also has good, clear text and individual illustrations.’

Caroline adds, ‘The instructions are clear, and the design and layout are attractive. There is much emphasis on communicating and generating a sense of enjoyment.

‘Most importantly, this book is about empowering the person with dementia.’

Lynne agrees, ‘It’s one to have for the toolkit – layers of moments of meaningful engagement.’

Chocolate rain
100 ideas for a creative approach to activities in dementia care by Sarah Zoutewelle-Morris
Garden magic

Caroline Branney highlights three very different garden-related books – for children, reminiscence and garden design.

Weeds in Nana’s garden

by Kathryn Harrison
(Flipturn, 2016),
32 pages, £8.25,

This story about a young girl and her Nana’s magical garden was both written and illustrated by Kathryn. It won a silver medal in the six- to eight-year old children’s category of the Wishing Shelf Book Awards, which are chosen by school groups in the UK.

Creating culturally appropriate outside spaces and experiences for people with dementia

by Mary Marshall and Jane Gilliard
(Jessica Kingsley, 2014),
168 pages, £19.99,

Good dementia care needs to start with the person’s individual story, preferences and needs, so understanding and acknowledging their cultural background is vital. This book looks at how to do this when creating outdoor spaces and experiences so that they can offer the most benefit for people with dementia.

Creating a garden: A Share-Time picture book for reminiscing and storytelling

by Judi Parkinson
(CreateSpace, 2017),
60 pages, £14.67,

This is a visual story book to help reminiscence, featuring a man digging a garden, clearing branches, pruning roses, and planting seedlings and flowers. The eighth volume of a series by Judi for people with dementia, it includes many beautiful images and comes in a handy, practical format.

Your turn

For the next issue, we invite you to read The dementia whisperer by Agnes B Juhasz (Hammersmith Health, 2016), 206 pages, £12.99, ISBN: 9781781610961.

Let us know what you think of this book by 11 September so we can share it in our next issue – email magazine@alzheimers.org.uk or write to the address on p3.

We have five copies to give away – email magazine@alzheimers.org.uk or write to the address on p3 by 18 August quoting ‘Whisper’ for a chance to win one (see p38 for terms and conditions).
Things to do

‘My husband lost all interest in things and it was frustrating for him if I suggested anything, so I left stuff lying around for him to fidget with when he felt like it. He still wanted the newspaper but he would just turn the pages and I doubt he ever read anything. It was a much calmer atmosphere once I realised and accepted that’s all he wanted to do. He never lost interest in walking though, and we did that together for as long as he could.’ caqqufa

‘I have had some success with dominoes. My mum likes counting the white dots. When playing cards, she looks at them and tries to put them in order... She likes to fold the clean laundry. She also likes looking at recipe books – ones with big, colour photos of the dishes. I’ve bought quite a lot of these from our local charity shops. I also bought a musical jewellery box and filled it with cheap pieces, mainly bead necklaces. Sometimes I can hear her playing with the box.’ Tin

‘I’ve recently gotten my mum back into knitting... I have discovered she can’t follow a pattern any more so I cast on sufficient stitches and away she goes! She carries on until we decide it’s a reasonable size and then we decide what we will turn it into. The project was a blanket for her great-granddaughter’s doll’s pram. Then we did a matching pillow. Now we are doing the same but with crochet. Again, she can’t follow a pattern so we just do one stitch. It’s looking good though.’ SnowWhite

‘My late husband refused to go anywhere without me, and didn’t want anyone coming in. However, I did get a man in two mornings a week while I went to work “to help with the garden”. My husband did accept that, and as his illness progressed, there was less pottering about in the garden, and more sitting with him, reading to him etc. The man did the heavier stuff in the garden that my husband could no longer manage, and my husband pottered about with him, digging holes! Then they would fix snacks together and lunch.’ LadyA

‘How about a small box or drawer of things that can be arranged and rearranged? The contents could reflect something that the person with dementia has been interested in – things such as knitting wool, assorted buttons or coloured pencils spring to mind... If you use something like coloured pencils, you could try leaving a drawing pad or colouring book with them too. Another option could be large-piece jigsaw puzzles, if they are able and interested.’ Slugsta

Join Talking Point at alzheimers.org.uk/talkingpoint

Talking Point members share advice about encouraging a person with dementia to keep active and engaged.
Later stage activities

A person in the later stages of dementia should be helped to be as stimulated and engaged as possible. Familiar tasks could still interest them, though they might be more interested in the process than end results. Small signs – a facial expression, sound or movement – may tell you how someone is responding to an activity.

Take time to talk to them, perhaps reading aloud, and play their favourite music. Gentle hand massage can also be soothing.

Some people enjoy handling pieces of fabric, dolls or cuddly toys, or being able to ‘fiddle’, such as by folding material or undoing knots. These can be incorporated into specially made activity blankets and cushions or ‘twiddle muffs’.

There may be ways to stimulate the person’s senses of smell and taste, perhaps using herbs and fruit.

Can they see pictures or brightly coloured objects from where they are, or could you position them to see a fish tank or window view? Is it possible to help them move around for a change of scene?

More ideas are included in our guide Taking part: activities for people with dementia, at a reduced price of £15 plus postage via our online shop.

Our shop also includes many activity products suitable for people with more advanced dementia.

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

Timeslide album competition

We have an Active Minds Timeslide album each for four lucky winners drawn from correct entries received by 8 September.

When was the first instant colour film introduced by Polaroid?

A. 1983  
B. 1963  
C. 1923

Mini bear competition

Six lucky winners drawn from correct entries received by 8 September will receive an Alzheimer’s Society mini bear – 8cm tall and super cuddly!

According to the famous song, if you go down to the woods today, you’d better...

A. ...say, ‘Big surprise!’  
B. ...flutter your eyes.  
C. ...go in disguise.

Send us your competition answers for us to receive by 8 September, 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.

Animal audio bingo competition

I Andersen in Lincolnshire won an Animal audio bingo game, and a Calmer by nature DVD was won by each M Cuthbert in Greater London, R Tyler in Surrey and K Blackburn in West Yorkshire. Answer: Bingo callers often refer to the number 22 as two little ducks.

Book giveaway

The five readers who each won a copy of Chocolate ran by Sarah Zoutewelle-Morris were A Parveen in West Midland, S Thomas in London, S Omand-Smith in Aberdeenshire, C Derry in Kent and M Bull in Dorset.

Dementia friends Heart range competition

S Merchant in Surrey won a T-shirt, mug and bag, and a mug was won by each A Hassan in West Midlands, L Wilkinson in East Yorkshire, T Baines in Merseyside, K Murray in Greater Manchester and J Green in Staffordshire. Answer: We expected 2 million Dementia Friends to have signed up this summer.
What we achieve
Four-fifths (81%) of respondents said they read all or most of the magazine, and nearly nine in 10 (87%) said they are likely to recommend it to others affected by the condition or involved in the dementia movement.

Over four-fifths said the magazine helps them feel better informed about living with dementia (87%), in touch with the Society (83%) or that support is available if needed (82%). Three-quarters said it gives them ideas about how they can support the cause (76%), and over three-fifths that it helps them feel that others understand what they’re going through (62%).

Around half (48%) said they had been prompted to get more information, advice or support after reading something in the magazine, while around a third said they’ve found out more about research (36%) or done something differently to help deal with the condition in their everyday life (32%).

What you’d change
When asked how we could improve the magazine, the most common response was that it is great as it is (31%). More than one in 10 said better availability in places such as GP waiting rooms or libraries (17%), more input from people affected by dementia (14%), more to prepare people for the realities of living with it (14%) and more on research or facts about dementia (13%).

Who you are
Two-fifths of respondents said they used to be a carer (41%) and are generally interested in dementia (38%). Over a third said they have (35%) or had (35%) a relative or friend with the condition. A quarter said they are a carer now (26%), while 7% said they have dementia, dementia symptoms or mild cognitive impairment.

Over two-thirds (69%) have donated to us or helped raise funds in the last six months. During the same time, a quarter have used our services (25%) and more than a fifth have supported our campaigns (22%), while around one in 10 have taken part in dementia research (11%) or supported others as one of our volunteers (11%).
Unite with thousands at Memory Walk

Let’s take on dementia together. Walk to raise funds for a cure, to improve care and to support those affected.

Sign up now at memorywalk.org.uk