

Dementia together

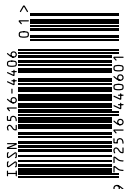
April/May 2018
Alzheimer's Society's magazine

Equipped to care
Care home training

Bridging a gap
Learning disabilities

Feel the love
Saying no to fear

Also in this issue
Dementia Action Week
Cupcake Day
Moving home
Self-adhesive signs



Good for the soul
It takes strength



**What will
you do for
Dementia
Action Week?**

21-27 May

Get involved in Dementia Action Week.

You can unite with us by putting up posters, sharing videos online or hosting an event in your local area – every action makes a difference.

To find out more visit alzheimers.org.uk/DAW





Welcome

News

Dementia Action Week 4

We're really happy to launch our brand new name, Dementia together, with this issue of the Alzheimer's Society magazine. It's vital that the title tells people exactly who the magazine is for – everyone in the dementia movement and anyone affected by the condition.

Thank you to the many readers, Dementia Friends Champions, service users, volunteers and supporters in Wales, England and Northern Ireland who helped us to choose this name. As you told us, Dementia together makes clear this is a magazine for everyone uniting as part of a social movement. It puts dementia first but also, as one group commented, 'The important word is "together".'

I hope you enjoy reading the magazine's real-life stories, news and ideas, and we look forward to sharing them with even more people in future.

Danny Ratnaike, Magazine Editor



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This is the April/May 2018 issue of Dementia together, the magazine for all Alzheimer's Society supporters and people affected by dementia.

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NI: Power to people

The Department of Health in Northern Ireland (NI) has published 16 proposals to reform care and support for people with dementia and other conditions.

In a report called Power to people, the proposals focus on people's rights and the need to facilitate and fund the diverse care and support on which they rely.

Since the collapse of NI's devolved government at the start of 2017, the lack of an executive means that public debate and decisions on care reform are yet to take place.

'Regardless of the status of the assembly, we are committed to include people with dementia, service providers and elected representatives as we press for the change that people so desperately need,' said Eliz Byrne McCullough, the Society's Policy and Public Affairs Officer in NI.

See alzheimers.org.uk/NIcampaigns to join our NI campaigns.



Social care in England: Get dementia on the agenda

Help Alzheimer's Society ensure that people with dementia are included in the government's plans for social care by joining our Fix Dementia Care campaign.

A consultation document, or green paper, on adult social care in England will give people the chance to feed back on government proposals, and we are calling for five main principles to be included.

These include making sure that people with dementia get the same support as people with other conditions, improving the quality of dementia care, ending catastrophic care costs for families, ensuring better value for money spent on care, and making the health and social care system more joined up.

We have been campaigning for a fairer social care system for years and want to ensure that people affected by dementia can influence future changes.

The 3 Nations Dementia Working Group – a group of people with dementia who work to raise awareness, reduce stigma and influence public policy – have already met with the Department of Health to have their say.

People affected by dementia are the largest users of social care and must not be ignored.

Join our Fix Dementia Care campaign at alzheimers.org.uk/fixdementiacare

New utilities guide

Our new dementia-friendly utilities guide aims to help firms better support and serve customers affected by the condition.

Aimed at water, energy and telephone companies, the guide includes key facts about dementia and the kinds of difficulties that dealing with utility companies can cause for people living with the condition, as well as examples of best practice from the likes of E.ON, BT and Wessex Water.

Representatives from the utilities industry attended the guide's launch event, along with Greg Clark, the Secretary of State for Business, Energy and Industrial Strategy.

Alzheimer's Society CEO Jeremy Hughes said, 'Too many vulnerable customers are being failed and urgent action is needed to change this.'

For our guide for utilities companies, visit alzheimers.org.uk/utilities or call 0330 333 0804.

People affected by dementia who experience problems with utility companies can call our National Dementia Helpline on 0300 222 1122 for advice.

Dementia Action Week: 21–27 May

Dementia Awareness Week is changing to Dementia Action Week. While raising awareness will always be important, we must go further and take action for people affected by dementia.

‘People are already aware. It’s action we now need. It’s help, it’s support,’ said Chris Roberts, an Alzheimer’s Society Ambassador who lives with dementia.

Between 21 and 27 May, we are asking people to unite and take actions big and small to make a difference to the lives of people affected by dementia. It could be as simple as being more patient in queues or making your workplace dementia friendly.

On 22 and 23 May, our Annual Conference will also take place at the Kia Oval in London, including a presentation on rights by members of the 3 Nations Dementia Working Group. Visit alzheimers.org.uk/conference to book your place and use the code ASAC18LWD for a 10% discount.

For more about Dementia Action Week visit alzheimers.org.uk/DAW

Wales action plan

The Welsh Government has launched a new Dementia Action Plan to set out its strategy for Wales to become a dementia-friendly nation. It pledges to respect the rights of people with dementia to feel valued and live as independently as possible in their communities.

This follows Alzheimer’s Society Cymru’s successful #45000reasons campaign, which called for a national dementia strategy.

It also draws on the Dementia Statements – these set out what people with dementia have the right to expect, and were compiled by people living with the condition in a process facilitated by the Society.

Alzheimer’s Society Cymru worked closely with the Welsh Government and DEEP (the Dementia Engagement and Empowerment Project) to make sure people affected by dementia had their say throughout the plan’s development.

The Welsh Government is also considering options for a new tax to better fund health and social care.

‘We’re excited that they are trying to address this issue but we’re also cautious, as we don’t want proposals that have negative side effects for people affected by dementia,’ says Morgan Griffith-David, Policy Officer at the Society.

‘People with dementia must be able to meaningfully influence the format of any new tax.’

See alzheimers.org.uk/walesstrategy17 for more about the plan and our campaigns in Wales.

The UK Dementia Research Institute is our biggest ever investment in dementia research. The government initially committed £150 million towards it, along with £50 million from us – which we will raise with your support – and the same from Alzheimer’s Research UK. In March, the government announced a further £40 million to build the institute’s hub at UCL in London.

What’s special about the money the Society is investing in the institute is that it won’t only fund biomedical research to find drug treatments for tomorrow. We are also funding research to improve care and bring benefits to people affected by dementia today.

This summer, we’ll appoint an Associate Director at the institute to lead this kind of research. They will lead an innovative care research programme, finding new ways to help people live well with dementia. We’ll be involving people affected by dementia in decisions about this research wherever possible.

We’ve already seen great progress through Society-funded care research. We developed training that dramatically improves dementia care in residential and nursing homes using the findings of work at King’s College London, and our centre of excellence at Newcastle University is researching better support after diagnosis. These are just two examples – with the UK Dementia Research Institute’s contributions, we can look forward to much more.

Jeremy Hughes
Chief Executive Officer



Heavy drinking and dementia

It can be hard to know what to believe when reading health stories in the news. This has been particularly true with recent reports on whether drinking alcohol increases the risk of developing dementia.

The BBC, Daily Express and The Guardian all reported in February that 'heavy drinking' increases the risk of early-onset dementia, but what does 'heavy drinking' actually mean? Is it that second pint, or the twelfth?

The study behind these headlines looked at people with early-onset dementia who had been admitted to hospital. Over a third of them had a form of dementia that was caused by sustained alcohol abuse. Alcohol-related brain damage (ARBD), caused by years of excessive drinking, includes Wernicke-Korsakoff syndrome and alcoholic dementia. A further 18% of people in the study had a diagnosis of alcohol abuse alongside their early-onset dementia diagnosis.

So far, this study and others have not provided enough evidence to say that mild or moderate alcohol consumption causes forms of dementia such as Alzheimer's.

If you drink alcohol, we advise not drinking more than the NHS recommended 14 units per week. That means drinking no more than six pints of lager or six 175ml glasses of wine a week.

If you are concerned about your alcohol consumption, visit your GP to discuss ways of cutting down and the support on offer to you.

For our **Dementia: Reducing your risk (35) booklet**, see alzheimers.org.uk/publications or call 0300 303 5933 (local rate) to order.

Updated factsheets

Our factsheet **Care homes – when is the right time and who decides?** (476) has been updated, as have **Grief, loss and bereavement** (507) and **Aggressive behaviour** (509).

For these and other publications, visit alzheimers.org.uk/publications or call 0300 303 5933 (local rate) to order.



Power of attorney refunds due

Many people will be entitled to a partial refund from fees paid to the Office of the Public Guardian (OPG) if they've registered a power of attorney in the last few years.

If you paid an application fee to register a Lasting power of attorney or Enduring power of attorney in England or Wales with the OPG between 1 April 2013 and 31 March 2017, then you may be due some money back.

For more details or to make a claim, visit www.gov.uk/power-of-attorney-refund or call OPG on 0300 456 0300 and select option 6.



Cupcake Day is back on 14 June!

Raise money and rise against dementia by hosting a Cupcake Day at home, work, school or anywhere else. Join us and we'll send you a scrumptious new fundraising kit, bursting with new games and decorations.

Sign up for your free fundraising kit at cupcakeday.org.uk or call 0300 222 5770 (local rate).

LPA gifts guidance

Legal guidance about when people who've been appointed as someone's deputy or attorney in England or Wales can give gifts on their behalf has been updated by the Office of the Public Guardian.

If you're appointed under a power of attorney or by a court to make decisions about someone's property and financial affairs, there are very limited situations when you can spend their money on a gift from them. A health and welfare attorney or deputy cannot do this. Visit www.gov.uk/opg or call 0300 456 0300 for more information.

In briefs

Personal health budget survey

NHS England wants to hear your experiences of personal health budgets and integrated personal budgets to improve how people affected by dementia are able to use them.

Personal health budgets and integrated personal budgets – funded wholly or partly by the NHS – are available to some people in England. They aim to help people design the kinds of care and support that they receive around what matters most to them.

If you have one of these budgets, share your experiences at www.myonlinesurvey.co.uk/phbsurvey before the end of April.

One Giant Leap

Have you got what it takes to make One Giant Leap during Dementia Action Week? Join hundreds of Society supporters on 27 May who are taking to the skies across the UK for a sponsored tandem skydive.

To sign up visit alzheimers.org.uk/skydive

Alzheimer's Show

The Alzheimer's Show offers jargon-free advice, usable tips and practical tools for people affected by dementia and memory loss. It takes place from 8–9 June at Olympia London, and entry is free for people with dementia. Quote ASOC18 for a 50% discount at www.alzheimersshow.co.uk/tickets or call 01892 723195.

Good for the soul

Despite enduring a series of health and other problems, Abdul-Fady Othman refuses to feel sorry for himself. [Gareth Bracken](#) meets a man who takes strength from supporting others.

Quick read

Abdul-Fady Othman, 77, who has Alzheimer's disease, thrives on supporting other people with dementia, despite his own health issues.

Abdul-Fady, who was bought to England as a teenager by a Church of Scotland missionary, has experienced alcoholism, cancer and schizophrenia.

His wife Małgorzata is a great source of support, as is his local day support service, which provides fun and fellowship.

He enjoys helping others and wants people to support those whose health issues may not be visible.

Throughout his eventful and sometimes difficult life, Abdul-Fady Othman has overcome alcoholism, schizophrenia and cancer, not to mention divorce and a period of homelessness.

His latest challenge is Alzheimer's disease, which he is facing with the support of his wife, a strong sense of perspective and a desire to help others.

Guardian mother

Abdul-Fady was born in Aden – now in southern Yemen – in the early 1940s. At the time it was a British colony, a distinction that Abdul-Fady is keen to underline.

'My passport doesn't say Yemen, I was born in Aden under British rule,' he says.

'I've never applied for a Yemeni passport and I never will.'

Abdul-Fady, 77, doesn't know many details of his earliest days, other than that he was left in the hospital by his biological mother. He suspects she may have been underage or unmarried.

He was raised by a Church of Scotland missionary who had come to Aden to help run hospitals. She took on Abdul-Fady and two other children, bringing them up as her own.

'I call her my guardian mother, she could never be called a foster mother,' he says.

'I had a Scottish mother, English father, a brother who was Jewish, a sister who was Arab, and me of Somali origin – it's complex!,' he laughs.

'But the marvellous thing was that we lived as a family, getting on with each other very well.'

Abdul-Fady arrived in London in 1954, when he was 13, on a day so cold he could see his breath.

'I remember coming down the gangplank at Tilbury Docks and thinking, "Mummy, there's smoke coming out of my mouth!" I didn't even have a clue what snow was.'

Total breakdown

After spending 10 years working as a stock clerk for an oil company, Abdul-Fady embarked on a series of jobs including forklift truck driver, labourer and steelworker.

'Every two years I went from job to job, chasing the money,' he says.

'I always moved on for more money because there was something developing in me all the time that wasn't very good – alcoholism.'

'You need money to drink, you need money to be in a bar.'

'I had the family and a mortgage but I think I wanted to live the life of a single man.'

Abdul-Fady eventually experienced what he describes as a 'breakdown in the head'.

'I just couldn't work anymore, couldn't manage anymore. There was a total breakdown in the marriage – we just couldn't live with each other.'

'I went downhill and downhill. I slept rough in the street, in the station, not looking for a job.'

After 10 years of what he calls 'dossing around and doing nothing', Abdul-Fady somehow got his life back on track.

'I think it was my upbringing in the church. I came home one day and just got on my knees and said a prayer,' he says.

'I went into detox and began looking for a job.'

Period of hell

Abdul-Fady later worked as a security supervisor for HM Customs and Excise, but became troubled by hallucinations and paranoid thoughts, eventually being diagnosed with schizophrenia.

'That was a period of hell,' he says. 'All the time, voices in your ear and seeing things.'

'You wouldn't believe how I walked up and down those streets thinking to myself, "He's looking at me, she's looking at me." It's a horrible life.'

Abdul-Fady was still drinking and having these distressing experiences when he met his second wife, Małgorzata, a Polish tailor and machinist, in 2006.

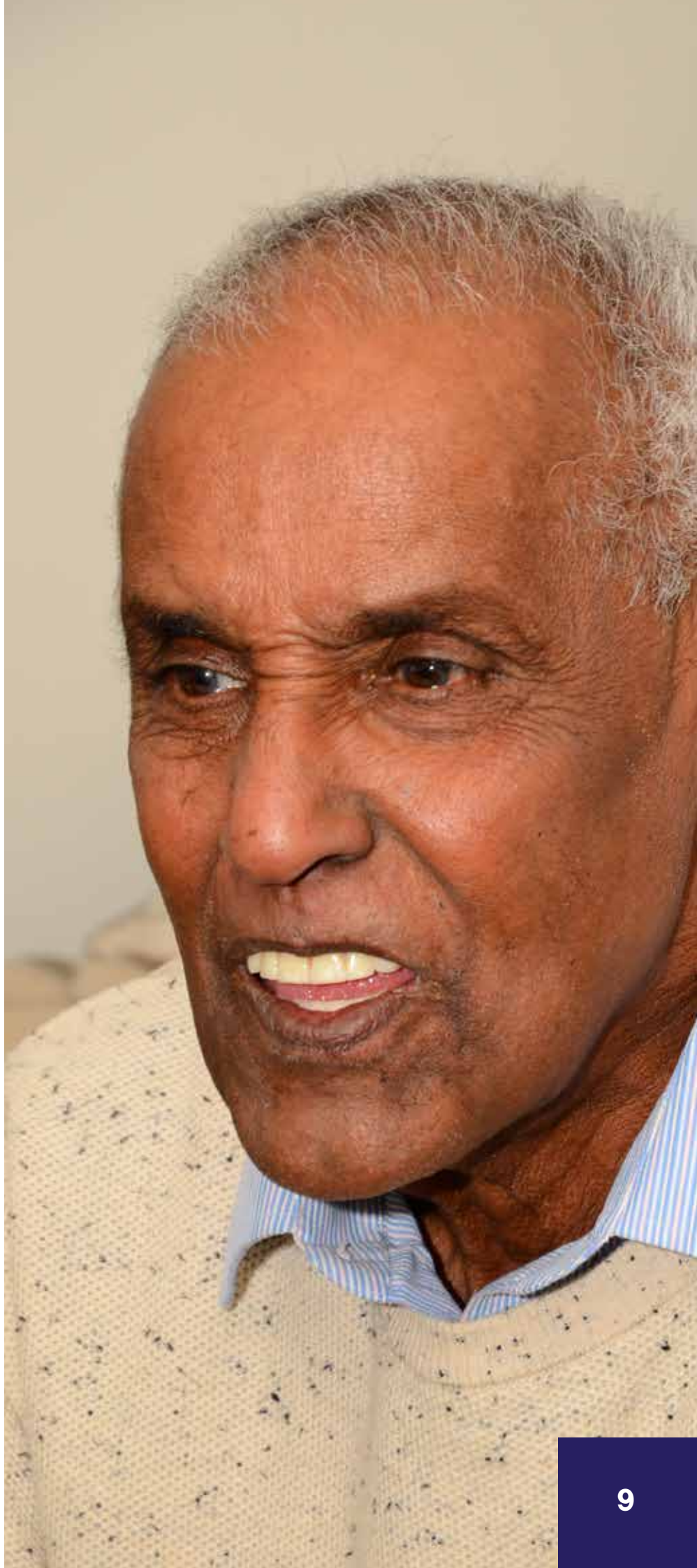
Małgorzata told him that if he wanted to be with her, then he had to stop drinking. He did, and the voices in his head began to clear.

Abdul-Fady later developed prostate cancer, but it was caught early and treated with radiotherapy, and thankfully hasn't returned.

However, Małgorzata then began to notice new changes in Abdul-Fady's behaviour. Previously he would never have gone outside their west London home without changing into nicer clothes, but he started going out in his indoor clothes without showering.

He also began to have memory problems, as well as feeling lethargic.

'I was forgetting everything, not registering things,' says Abdul-Fady. 'She'd tell me to do something and I would forget pretty well immediately.'



'I was also sleeping half the time – always tired. It took me all my effort to go and poach an egg. It was horrible. I'd watch a film and not know what the hell was going on, because I'd gone to sleep in between.'

A brain scan and further tests led to a diagnosis of Alzheimer's in February 2014.

Abdul-Fady started taking medication, but this was soon stopped after he experienced dramatic side effects.

'On the third night of taking those tablets, I smacked the pillow and missed my wife by centimetres,' he says.

Abdul-Fady was then told that the medication can have side effects for people who have a history of walking or talking in their sleep, as he did.

'Yet the doctor gave me the tablets without checking beforehand!' he says.

Fun and fellowship

Abdul-Fady, who also has arthritis and diabetes, credits his wife with helping him through some tough times.

'She's a godsend, an angel,' he says. 'I could have gone to pieces without her looking after me so well.'

He has also been boosted by attending a day support service in Hammersmith, run by the Society, twice a week.

'I go there and get fellowship,' he says. 'You've got quizzes, bingo, music and dancing.'

'It's getting people working together, enjoying each other's company and stretching our minds – I need that.' Abdul-Fady enjoys supporting other members of the group, something that he believes reflects a new aspect of his personality.

'I'll help somebody who's not good on their legs to go from one side of the room to another, or I'll take somebody who can hardly stand and have a dance,' he says.

'I feel I've changed. I've always put myself out that extra bit and got no reward for it, which made me angry, but now I'm not angry if I don't get any reward for it. A nice feeling comes over me, it's good for the soul.'

Seeing people whose dementia is more progressed than his own has spurred Abdul-Fady on to be as supportive as possible.

'It makes me work harder to help people like that – I want to see them happy,' he says.

'There's a lot of loneliness with Alzheimer's but you can make people laugh, join in and have fun.'

Better place

Abdul-Fady is especially aware that it may not be obvious to onlookers that someone has dementia, or many other conditions.

'You could have a problem but people see you bright-faced, laughing and joking and think, "There's nothing wrong with him,"' he says, 'but you don't know the pain within people.'

Abdul-Fady doesn't seek others' sympathy, preferring that they focus their attention on people who he feels are in greater need.

'If people don't notice my dementia, fair enough. I can understand them not seeing it,' he says. 'But there are certain people who need support – you've got to notice them.'

As he reflects on the past, Abdul-Fady also refuses to concern himself with what might be around the corner. 'I'll try and do as much as possible while I'm here. I really don't think about how long I'm going to last,' he says.

'I don't worry about it because I know that when I die, I'll be going to a better place.'

'I just plough through, year after year, ever faithful to my wife and friends.'





Photographs: Derek Goard

Next steps

- To hear Abdul-Fady's story in his own words, and our other magazine podcasts, visit alzheimers.org.uk/dtmpodcast
- For our Keeping active and involved (1506) booklet, 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

A friendly call

Telephone Side by Side volunteers are providing regular phone contact for people with dementia in Wiltshire.



‘That somebody takes the time to give you a ring, ask how you are, have a chat – it’s nice when somebody makes that effort.’

That’s just one of many appreciative comments from people with dementia in Wiltshire who have joined our telephone Side by

Side service. A phone call may seem like a small thing, but the right call at the right time can make a world of difference.

Alison (pictured) saw how people could be impatient with her father and mother-in-law when they had dementia years ago. Now a telephone volunteer, she says she’s able ‘to be that person who will listen patiently, reassure and value each individual.’

Rodney Smith, who has Alzheimer’s, is someone else Alison calls regularly. He certainly values hearing from her.

‘We talk about life and everything, what we’ve done in the past,’ says Rodney, 73. ‘She had time in the forces and I was in the army as well – so we have something in common.’

Regular phone calls

Through Side by Side, volunteers usually meet people with dementia face to face, supporting them to continue to do whatever they love doing. However, some people prefer regular phone contact, and an increasing number of areas offer this too.

‘I have five service users who I telephone regularly, once or sometimes twice a week,’ says Alison.

‘They’re all completely different. Four women and one man, all isolated in their own ways, who look forward to my calls and never run out of things to chat about now that they know me.

‘Sometimes they can be very down when I call, but I aim to leave them in a happier frame of mind. We have lovely conversations, full of humour and laughter.’

Good opportunities

Diane Jenkins, the Side by Side Co-ordinator for Wiltshire, was keen to offer a phone service, particularly because it can be harder to find a nearby volunteer in rural communities.

‘It’s given people who’ve been waiting a while the opportunity to have a good relationship with others when they’ve been isolated previously, enabling me to look for the best face-to-face matches for them,’ says Diane.

‘This can also work well for people who physically may not be able to get out and about, but who still have social connections and want the opportunity to talk to someone.’

In addition, it means more ways to get involved for volunteers without transport or who – like Alison – have a disability that affects how much they can travel. It’s a flexible role, only needing half an hour or so to be put aside for a call.

Prepared to chat

Everyone involved in Side by Side has a ‘one-page profile’ about them and their interests. This helps people with dementia to select volunteers, and it can be useful in prompting conversation on the phone too.

Diane knows what to look for in a telephone volunteer like Alison. ‘Being interested in people and what they have got to say, being a good listener – and being prepared to chat about anything!’

It’s clear that Alison fits the bill, not only from people’s feedback, but also from how it affects her.

‘In a nutshell, I love what I do,’ she says. ‘I feel useful and valued.’



For more about Side by Side, visit alzheimers.org.uk/sidebyside
Call 0300 222 5706 (local rate) or email volunteers@alzheimers.org.uk to find out more about volunteering.

Inspired to bake

A baking enthusiast in Belfast, looking forward to Cupcake Day 2018 on 14 June, shares her success from last year.

When Tanya Haggerty and her family raised over £900 for last year's Cupcake Day in Belfast, they had one clear inspiration – their Nanny Pearl.

'Until my Nanny was diagnosed, I'd heard of dementia but never had any connection to what it means to have a loved one who has it,' says Tanya, aged 32. 'I had no idea how hard it can be on families.'

'I got my love for baking from my Nanny Pearl. She inspired me – not just in baking but in life.'

'She gave me a mixing bowl when I first got the baking bug. Although it's only a plastic bowl, it makes me think of her every time I bake.'

Tanya (pictured with Nanny Pearl below left) got involved in Cupcake Day because she knows that supporting Alzheimer's Society makes a difference.

'Anything we do is for #TeamPearl and all the other families who are affected by dementia.'

All out

Tanya, her sister Julie (pictured below right) and mother went all out for Cupcake Day. 'Between us, we made cakes, desserts, tray bakes and buns – a lot of them! We held events in my sister's school, and letters were sent out to parents to make them aware of the bun sale, which was the same day as their sports day. We also made a small selection for the staff room.'

'My mum brought a load into her work, and the home my Nanny lives in were kind enough to let me hold an event too.'

Tanya sold any leftovers to colleagues at work. 'We played the games and used the balloons and banners that were included in the free fundraising kit.'

Very special

Tanya's looking forward to this year's Cupcake Day. 'I really enjoyed Cupcake Day and will definitely do it again. There is something very special about people coming together for the same cause.'

'I love baking and it was lovely to see so many people enjoy the finished product. It's a fun way to raise awareness and money for an amazing charity.'

Sign up and get your free fundraising kit for Cupcake Day 2018 on 14 June at cupcakeday.org.uk or call 0300 222 5770 (local rate).

smile.amazon.co.uk

Shop for us

You can now raise money while shopping online thanks to AmazonSmile. If you select Alzheimer's Society as your chosen charity, then Amazon will donate to us every time you order something from them, at no extra cost to you or us.

Visit smile.amazon.co.uk and select us as your charity.

Book of You



An app created by a Welsh social enterprise that you can use to make a personalised Book of You – using pictures, audio and video – is available to individuals across the UK for £25. You can decide who can access your Book of You on any online device to help reminiscence and person-centred care.

See www.bookofyou.co.uk or call 01492 555381 to find out more.

Volunteers' Week

From 1–7 June, Volunteers' Week is a great time for volunteers to share their experiences and for new people to get involved.

Tell people about your volunteering on social media from 1–7 June using the hashtag #VolunteersWeek.



Feeling valued

An African refugee is contributing to his new community in north Yorkshire by volunteering with us.

Alzheimer's Society volunteer Elie Ngoyi came to England in September 2013, after leaving the Democratic Republic of the Congo in central Africa for his own safety.

Speaking out

'I raised awareness of women's rights and spoke out against sexual violence,' says Elie, a doctor who specialised in sexual and reproductive health.

'I also spoke out against corruption committed by officials and people in government, so I was in trouble.

'I was fleeing persecution because of my political opinions and seeking a safe sanctuary.'

The recent history of the Democratic Republic of the Congo includes two devastating wars among other hostilities.

Elie worked in a conflict zone hospital and was also a doctor for CARE International, a charity that fights poverty and injustice.

Trust and belief

Elie, aged 45, now lives in Thornaby-on-Tees in the north-east of England, where he is studying towards being able to practise as a doctor in the UK.

He volunteers for Alzheimer's Society as a Dementia Advisor Volunteer, also attending dementia cafés and awareness-raising events.

'While in the process of my asylum application I wanted to make a contribution to the community,' he says.

'I provide information and advice to people about diagnosis, symptoms, how to cope with out-of-character behaviour, finances, employment and what kind of services they can get.'

Elie has gained a lot from his volunteering. 'I feel personal satisfaction and a feeling of wellbeing,' he says.

'I'm not working as a doctor yet, but I am making a contribution to people's lives. That's important to me – I feel valuable.

'I have found an opportunity to share my experiences and learn more about people with dementia. They have inspired me a lot.

'When someone is living with dementia, it's also about their family,' he says. 'When you build a relationship with them, it's one of trust and belief.'

Elie (pictured below with service users Olive and Roy Hufford) says his Society colleagues have become like family to him.

'We have one thing in common, we are united against dementia – that's in our genes,' he says.

Overlooked and misunderstood

According to Elie, dementia is largely overlooked and misunderstood in the Democratic Republic of the Congo.

'Unfortunately, it's really different in my country,' he says. 'Dementia is just ignored by the majority of people. Because of political corruption, the health system doesn't work properly, so some illnesses are prioritised.

'Some religious people also accuse those with dementia of being affected by a spirit problem. They don't understand that the person needs support. It's ignorance.

'It should be the same as here in the UK – for all of Africa and everywhere.'



Find out about volunteering opportunities near you – visit alzheimers.org.uk/ volunteer or call 0300 222 5706 (local rate).



Becoming reality

Tim Shakespeare, Research Information Manager, updates us about progress on the UK Dementia Research Institute.

The announcement of the UK Dementia Research Institute's launch in 2016 was ground-breaking – a £250 million project bringing international expertise together to fight dementia and improve the lives of people affected by the condition.

Headquartered at UCL in London, the institute includes five other centres at Imperial College London, King's College London, and the universities of Cambridge, Cardiff and Edinburgh. Founding a world-leading research institute takes time, and it's been exciting to hear about new laboratories, equipment and researchers across the six sites.

In Edinburgh, scientists moved into dedicated labs to investigate how brain cells, the immune system and the brain's blood supply interact. The new facilities will benefit many researchers, including those funded by others – the more collaboration, the more knowledge sharing and the sooner we can identify new treatments and the best care.

My teammates brimmed with enthusiasm after returning from the Cambridge centre. They saw one of our key ambitions – attracting scientists at the forefront of their fields to focus their efforts on dementia – becoming a reality.

Visiting Cardiff, we heard from 11 researchers looking into the role that our immune system may play in the development of dementia from different angles, working together to speed up progress.

I've only described a fraction of what's happening – there are 28 research programmes starting already and we're expecting this to grow to 50. The institute is set to make a huge impact in coming years – watch this space! Find out more about this joint project between us, the Medical Research Council and Alzheimer's Research UK at www.ukdri.ac.uk



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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



Perfect fifth

Exeter's Singing for the Brain group celebrated its fifth birthday with cake and a joyful rendition of Happy birthday, led by singing leader Jacky Forbes. The group is one of many that bring people with dementia and carers together to enjoy and benefit from the power of shared song.

'Hidden in the fun of a Singing for the Brain session are activities that build on the well-known preserved memory for song and music in the brain,' said Claire Tatton, Services Manager for Devon. 'Even when many memories are hard to retrieve, music can be easier to recall.'

'Anyone affected by dementia is welcome whether you already sing or not. People from all walks of life, and at different stages of dementia, enjoy Singing for the Brain and many come back for more.'

Find dementia support and activities near you, including Singing for the Brain, using our online directory – see alzheimers.org.uk/dementiaconnect



Firefighting dementia

Staffordshire Fire and Rescue Service has unveiled an Alzheimer's Society-branded fire engine to highlight our work with them, Tamworth Dementia Action Alliance and Tamworth Borough Council.

Fire service staff in the town are taking part in refresher dementia awareness training so they can better support and provide safety advice for people affected by the condition.

'This was a fantastic opportunity to team up with these organisations and show our continued support to making Tamworth a dementia-friendly community,' said Station Manager Martin Weaver. 'The crews have really embraced the updated training and will use their work in the community as an opportunity to help support this very worthy cause.'



Causeway action

A group of people affected by dementia in Northern Ireland have met with elected representatives to make their local concerns heard.

Members of Causeway Focus Group, facilitated by Alzheimer's Society, want to address a lack of provision of dementia nursing beds, the need to improve the hospital admission experiences of people affected by dementia, as well as other issues affecting them personally.

Adrian Friel, our Northern Area Services Manager, said, 'I am delighted we now have a very active group in Causeway. They will continue to raise issues affecting people living with dementia and those supporting them in the local area.'

East Londonderry MLAs Caoimhe Archibald (Sinn Féin) and John Dallat (SDLP) committed to follow up on the group's concerns with party colleagues.



Atlantic Ladies

A three-woman crew raised over £7,600 for Alzheimer's Society while smashing three records rowing 3,000 miles across the Atlantic.

When the Atlantic Ladies – Elaine Theaker (pictured) from Abergavenny along with Sharon Magrath and Di Carrington from Shrewsbury – completed the Talisker Whiskey Atlantic Challenge, they became the first female trio to row any ocean and the oldest female crew to row the Atlantic. Di, aged 62, is also the oldest woman to row any ocean.

In a boat measuring only 7m by 2m, they rowed from the Canary Islands to Antigua, arriving in the early hours of 13 February after over 60 days at sea. Visit www.atlanticladies.co to see more of their amazing journey.

Have you visited our online shop yet?



You can find a wide range of products in our online shop. We have daily living aids, exciting branded merchandise and gifts for all the family.

We ask people with dementia to try our products. This way we can offer you the best products to make everyday tasks a bit easier.

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

100% of our profits go towards supporting people affected by dementia and finding a cure.

Feel the love

Having supported her husband from diagnosis to his death, Pat Collard understands how dementia changes relationships. **Gareth Bracken** meets a woman who lost her closest companion.



Diagnosed with dementia back in 2013, Pat Collard's husband, Mick, died just before Christmas last year.

'The funeral was a celebration of Mick's life and went better than we could have hoped for. The celebrant said you could feel the love that day,' says Pat, who lives in Cottingham in Hull.

For Pat, 68, it concluded a story that had begun some 50 years earlier.

Family man

Pat, who left Scotland as a teenager, met Mick in early 1968 at college in Hertfordshire. They married in 1970, the week after Pat completed her teacher training.

They lived in various parts of Essex – with a two-year spell in

Antwerp, Belgium sandwiched in between – before settling up north in more recent times.

Pat worked as a teacher before moving into the local authority's education advisory service, while Mick was a research engineer for telecoms firms including Marconi.

The couple had two sons, both now in their 40s, as well as grandchildren.

'Mick loved his work but it was never his reason for living,' says Pat. 'His immediate family was always most important.'

A passion of Mick's was their 15th century home in Felsted, Essex, which he spent 20 years restoring in his spare time. The couple also enjoyed travelling and had many memorable holidays together at home and abroad.

Quick read

Pat Collard, whose husband died last year, has been sharing her experiences of how dementia can affect a close relationship.

Mick Collard was diagnosed with atypical Alzheimer's disease in 2012, having initially struggled to find the right words in conversation.

The day Mick moved into full-time residential care was the hardest of Pat's life, even though she knew it was best for him.

Although dementia affected their relationship in fundamental ways, Pat thinks they succeeded in not allowing fear of the future to undermine their present.

Dementia denial

It was back in 2009 or 2010 that Mick began having difficulty with finding words – he could describe certain objects or items, but not actually name them.

‘I now realise he was telling the GP that he was having problems remembering people’s names. He wasn’t being honest,’ says Pat.

‘So of course the GP said there was nothing to worry about and it was normal. He had an element of denial because he could still do everything else. He maintained such a good memory and a brilliant sense of direction for a long time.’

Eventually a clinical psychologist diagnosed Mick with aphasia, where someone experiences problems using language correctly.

Mick had further tests at the Cerebral Function Unit in Manchester, which led to a diagnosis of atypical Alzheimer’s disease in 2013.

The couple decided to tell people about Mick’s dementia so they could better understand his behaviour.

‘We compiled an email for friends and put the decision to them as to whether they wanted to continue on our path – nobody rejected us,’ says Pat.

As Mick’s dementia progressed, he lost the ability to write as well as his understanding of numbers and money.

‘You slide into them being less able and you doing more things for them,’ says Pat.

No man’s land

Pat wanted to get any support she could, and started going to an Alzheimer’s Society memory café with Mick. However, it proved more useful for herself than her husband.

‘I found it interesting and helpful, and it meant I found out about the Carer Information and Support Programme

(CrISP), which is a brilliant course,’ she says.

‘But Mick asked, “What are we doing here?”, because other attendees had more advanced dementia, so the activities were more suited to them. Mick couldn’t join in the carer chat either, so he was in no man’s land.’

More useful to Mick was something that has since developed into our Side by Side service. This paired him with a local volunteer for enjoyable trips to museums and drives in the car.

Pat also took advantage of a free local service providing replacement (or respite) home care, and employed a private carer to take Mick out.

Hardest day

In May 2017, Pat was offered replacement care for Mick at Woodleigh Manor, a nearby care home.

‘The impact of that was huge, as it made me realise



what our “normal” had become,’ she says.

‘I realised that life in the outside world had become too difficult for Mick, so while I thought I was doing the right thing in keeping him at home, it was making it difficult for him.’

The following month, Pat accepted a permanent place for Mick at Woodleigh Manor.

‘I always said that Mick would never go into residential care to make my life easier – it would always be about him, not me,’ she says.

‘On 5 June 2017, I took him. It was probably the hardest day of my life. He didn’t know he was going and I couldn’t tell him.’

‘Everything in my brain said I couldn’t do it, but I kept packing the case. It was really hard.’

‘He had no idea he would never be coming home again, ever. That’s a momentous thing to do.’

Pat visited the home regularly and took Mick out for trips.

‘He couldn’t name me, but he knew me and knew our relationship,’ she says.

From October, Mick needed end of life care and he died on 22 December, aged 71.

‘The funeral was the day before the 50th anniversary of the day we met. That somehow seemed to close a circle,’ says Pat.

Lost love

Pat speaks openly about the impact that dementia had on her and Mick’s relationship.

‘Our working lives were separate, but apart from that we did everything together. We learned to be adults together, dealt with the issues of life together. But dementia drives a horse and cart through the partnership aspect of togetherness,’ she says.

‘As dementia progressed, it changed to “carer” and “cared for”. I was a wife who cared, then a carer. Towards the end, there was no aspect of wife left. I was married but I was a “midow” – a married widow – a term I saw on Talking Point.’

‘I feel selfish saying it, but I lost my freedom. I lost companionship. I lost support. And ultimately I lost his love as it had been – a very caring love.’

‘The biggest issue was that the one person I had always been able to turn to was the one person I couldn’t discuss the biggest challenge of my life with.’

As well as sharing her story with us, Pat has spoken at a dementia conference and taken part in interview panels for new staff at Alzheimer’s Society.

She says this is a way of ‘taking a shot back at dementia’ and regaining some of the control that the condition and its progression took away.

As she reflects on the challenges of recent years, Pat recalls a vow that she and Mick made following his diagnosis.

‘We agreed that we would not let fear of the future take away our present,’ she says.

‘It was a hard one, but I think we managed it.’



Atypical Alzheimer’s disease

Sometimes, people’s brains can be affected by the same kind of damage that lies behind Alzheimer’s, but it can begin in a different part of the brain. Alzheimer’s usually damages the hippocampus first – an area that is important for memory. If other areas of the brain are affected before this, then people may experience very different initial symptoms.

Three types of atypical Alzheimer’s are posterior cortical atrophy (PCA), logopenic aphasia and frontal variant Alzheimer’s disease.

In PCA, damage to rear areas of the brain can make it harder for the person to process information about what they see and where things are in relation to each other. Early symptoms often include problems with identifying objects, reading or judging distances when going downstairs.

Damage to areas of the left side of the brain may cause logopenic aphasia, where someone has laboured speech with long pauses.

Frontal variant Alzheimer’s damages areas at the front of the brain. This affects planning and decision-making, sometimes causing behaviour that is socially inappropriate or which seems uncaring.

Atypical Alzheimer’s is rare among people aged over 65, but it could be the cause of dementia in up to a third of people diagnosed at a younger age.



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

Equipped to care

Specialist training can help care home staff provide better support for people with dementia. Gareth Bracken sits in on a session provided by Alzheimer's Society.

Quick read

Alzheimer's Society offers training to care home, home care, hospital and hospice staff so that they can better support people with dementia.

Staff at Manton Heights Care Centre in Bedford took part in a one-day course called 'Responding to distressed behaviours'.

The course included exercises and discussions about different types of behaviour, how people communicate and appropriate use of body language.

Staff said the course boosted their knowledge, which they felt would benefit the home's residents.

It's a staff training day at Manton Heights Care Centre in Bedford, as people who support residents with dementia attend a course called 'Responding to distressed behaviours'.

Provided by Alzheimer's Society, the course helps staff to recognise when people at the care home are distressed, identify what might be triggering it and find better ways to support them. It also looks at how damage to the brain caused by dementia might affect someone's behaviour.

Attending today are care assistants, healthcare assistants and senior healthcare assistants, who all completed a more basic course the previous week with the same trainer, Caroline Hayden-Wright.

'There's the factual side of it, which we want people to understand, and then the skills about how to interact with residents,' she says.

Interpreting behaviour

An early exercise sees staff in small groups ranking a list of behaviours – including spitting,

making physical threats and using racist language – in order of which they would find most offensive.

The groups come up with vastly different opinions, agreeing that it depends on the person with dementia, the staff member and the precise nature of the behaviour, among other factors.

Staff are then asked to consider the difficulties that people with dementia might have in communicating and expressing their physical and emotional needs.

Caroline links this back to the previous list of behaviours, explaining that people who behave in those ways are trying to communicate something.

Staff are also asked to solve word puzzles, which underline the need for creativity when interpreting what people with dementia are trying to communicate.

Caroline says that key skills include staying calm, picking up on emotional cues and looking for the true meaning of alternative words or sounds, which a person with dementia might use when trying to describe something.



She also talks about the need for validation and reassurance, rather than correcting someone with dementia.

‘We’re connecting with that person’s emotional memory,’ she tells the group.

Stressful situations

Asking group members how they would deal with various stressful scenarios in their personal lives provokes a discussion about the different ways in which they would react.

Caroline encourages staff to consider that a resident’s response to a situation isn’t always going to be because of their dementia – their personality, life history and environment can all play a part in someone feeling anger, anxiety or apathy.

Body language is also addressed, with Caroline explaining what stances might feel confrontational to a resident, then showing more appropriate alternatives.

In a practical activity about vision, staff experience what it’s like to be surprised by someone when your peripheral vision is limited.

As the training draws to a close, staff members praise both Caroline and the course.

‘I’m seeing care work differently to before,’ says one. ‘You boost our knowledge.’

Another says, ‘I think every care worker should get this sort of training. It benefits the residents.’

Eye opening

To deliver a successful course, Caroline has to understand the needs of the group, as well as the personalities within it.

‘My approach is to connect with them as people,’ she says. ‘You begin to understand their learning styles and the issues that are relevant to them.’

‘Although I do have to present facts, it’s about being an equal, not a teacher, and giving them space to tell their stories.’

Tina Colley, Manton Heights’ Deputy Home Manager, says the training is part of the home’s efforts to become more dementia friendly.

‘Residents were showing some “challenging behaviour”, so we wanted to give staff the knowledge of how best to deal with these issues, as some of them had only done more basic e-learning previously,’ she says.

Tina was impressed with how the training was delivered.

‘I enjoyed it,’ she says. ‘There was a lot of group work and interaction.’

During the day, many of the staff spoke about their experiences of supporting people with dementia.

‘The way they reflected on how they apply the training, even

without realising it, has been really positive to see,’ says Alex Peddar, Team Leader of the home’s Advanced Dementia Unit.

‘Away from the courses, staff have also been talking about how much they’ve gained and how it’s opened their eyes.’

Quality of life

This course is one of many run by Alzheimer’s Society for care home, home care, hospital and hospice staff, covering everything from basic dementia awareness through to end of life care.

The Society also provides training for businesses such as insurance firms and banks who want to better support customers with dementia.

‘I want us to be recognised as the best for dementia training – we see ourselves as the experts, and we’re passionate about that,’ says Raj Kapoor, Head of External Training and Consultancy.

The courses are tied to the Society’s latest five-year strategy, including our New Deal on Support, where we aim to train 20,000 health and social care professionals by 2022. Better quality care is also a focus of our Fix Dementia Care campaign.

‘The most important thing is improving quality of life for a person with dementia,’ says Raj. ‘That’s the ultimate outcome.’



Next steps

- For more about Alzheimer’s Society’s training and consultancy, visit alzheimers.org.uk/training
- Join our Fix Dementia Care campaign – visit alzheimers.org.uk/campaign to demand change.
- Read our Changes in behaviour (525) factsheet at alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Bridging a gap

People with a learning disability who develop dementia, and their carers, often don't get necessary support to understand the condition. **Gareth Bracken** visits a Herefordshire project that's making a difference.

People with a learning disability have an increased risk of dementia. In particular, one in three people with Down's syndrome aged over 50 will develop dementia, and they are more likely to do so before age 50.

Our Learning Disability and Dementia project is supporting people in Herefordshire affected by both a learning disability and dementia.

It has been raising awareness and understanding, preparing people living and working with learning disabilities for the changes that dementia can bring, promoting useful resources and helping to join up relevant services.

'We didn't seem to see or hear about people with a learning disability – they were a "hard to reach" group for us,' says project manager Ginnie Jaques.

'I realised that people didn't have support or understanding – that bothered me.'

Adapted resources

Tracey Exell, a Dementia Adviser, has begun delivering Dementia Friends information sessions to people with a learning disability, using adapted resources created in partnership with MacIntyre, a learning disabilities charity.

'The group weren't scared or worried. They were glad that dementia was given a name and explained,' she says.

Tracey also holds Dementia Friends sessions for family carers of people with a learning disability who also have dementia, and for care staff who work with them.

These form part of wider discussions about the needs of people with both a learning disability and dementia, which also include viewing a short film.

Attendees include carers from a local Shared Lives scheme, who welcome adults with learning disabilities and other needs into their own homes, providing support as well as housing.

'There was a gap when my carers asked for dementia training,' says Dave Davies, Shared Lives Manager in Herefordshire.

'I could have sent them on a one-day course, but Tracey coming in with specific information has been very helpful. They were learning things that they could put into practice right there and then.'

Quick read

An Alzheimer's Society project in Herefordshire is supporting people affected by both a learning disability and dementia.

People with a learning disability, and those who care for them, have become Dementia Friends, increasing their awareness of dementia.

Carers are also offered additional advice and support – Lesley Howarth says she and her daughter have 'learned so much'.

Tracy Crum has a learning disability and has become a Dementia Friends Champion because she wants to make a difference.



Learned so much

As part of Shared Lives, Paige Talbot and her mother Lesley Howarth care for two women age 45 and 60 with learning disabilities and Alzheimer's disease.

'Tracey's session is very good, you get such a lot out of it,' says Paige.

Lesley says, 'It's very enlightening. I've watched the film twice and picked up new things the second time.'

Away from the sessions, Tracey is always on hand to offer advice, information and support. Lesley says their increased understanding means they can reassure the women in situations that could be distressing.

'I don't know how we managed before – we've learned so much,' says Lesley.

Paige agrees that they've picked up new strategies for dealing with the effects of dementia.

'Our patience has helped them to be more relaxed,' says Paige. 'We have learned to distract them or take them to another place.'

Tracey also suggested loading information about both women onto an iPad, so that useful details can be shared easily between home and staff at Aspire, the community hub they attend.

'It makes everything very transparent,' says Paige. 'If they're having a bad day, we can tell why – maybe their routine has changed.'



Photographs: Simon Hadley

Port in a storm

Another of the newly created Dementia Friends is Louise Macintyre, whose brother Peter has learning difficulties. Peter may also have dementia – his family and care home staff are awaiting MRI scan results after noticing behavioural and physical changes.

'The project is providing so much support for myself, Peter and everyone at his care home,' says Louise.

'It has come just at the right time for him – it's been a real port in a storm. They have given us so much information.'

Tracey has also worked with Peter's family to create a life story book, made up of family photos.

'They are getting to know Peter really well,' says Louise.

The project is also creating dementia-friendly support plans for people with a learning disability, taking into account their choices now and in the future.

Get people talking

Some people with a learning disability are also becoming Dementia Friends Champions – people who deliver Dementia Friends information sessions.

The first is Tracy Crum (pictured below left), who recently completed her training.

'I decided to become a champion because I want to help people understand dementia,' she says.

'I hope more people with a learning disability will become a Dementia Friends Champion, and that other people who work with a learning disability will understand what people with learning disabilities and dementia are going through.'

'I love being part of the project and want to make a difference.'

The team behind the project feel positive about its impact so far.

'People are living better, they've made changes,' says Tracey. 'Families were quite confused and didn't know how to support a person, but now things are calmer.'

Ginnie is pleased that people who were not aware of Alzheimer's Society now have a source of dementia support.

'We're breaking down the fear and getting people talking about it,' she says.

Next steps

- Our Easy Read factsheets, *What is dementia? (ER1)* and *Supporting a person with dementia (ER2)*, are designed for people with learning disabilities – see alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- Become a Dementia Friend or Dementia Friends Champion – find out how at dementiafriends.org.uk
- Visit alzheimers.org.uk/dementiafriendlycommunities for information about dementia-friendly communities.

A reader shares an account by her eight-year old granddaughter and we look dementia-related blogs.

My grandpa

My grandpa's name is Brian and he is 68 years old. Sadly, he has Alzheimer's, which means his memory is not so good.

He lives in a kind, caring and comfortable care home, which luckily is close to my granny's house. My family often goes to see him, take him out to a pub lunch or bring him back to my lovely granny's house.

My wonderful grandpa has grey hair and a wrinkly face. He wears a checked shirt, jeans, a grey jumper and comfortable slippers. Recently, he has become quite bent over and has a clenched hand. Grandpa's diet has changed in the last few years, however he still enjoys cake and ice cream. Grandpa has always liked football and driving fast cars.

I love my grandpa so much!

Ruby Dawkin, aged eight, Greater London

Jane Dawkin (Ruby's lovely granny) explains:

My husband Brian has young-onset Alzheimer's, now advanced. He was diagnosed in 2014 and is now in full-time care. It has been a very difficult journey, however I have been well supported by my family and my local Alzheimer's Society in Croydon.

My granddaughter Ruby wrote this for school homework, giving some insight through the eyes and thoughts of a very kind and caring young lady. I am so proud of her.

Congratulations to our letter of the month writer, who will receive a Boules game, part of the Gifts for children range in our online shop – visit shop.alzheimers.org.uk or call 0300 124 0900.

Ruby (far right) pictured below with grandpa Brian and her brother and sister, Zak and Sasha.



Your turn

Tell us what you think – write to Magazine Editor, Alzheimer's Society, 43–44 Crutched Friars, London EC3N 2AE or email magazine@alzheimers.org.uk

Letters for the June/July issue to arrive by 7 May. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

Dementia-related blogs

The dementia movement online.

Which me am I today?

If you like Wendy Mitchell's book (see p34), you'll also enjoy her entertaining and thought-provoking blog, called Which me am I today? A diary about her day-to-day life, it includes her thoughts on everything from Yorkshire tea to her cat. Visit www.whichmeamtoday.wordpress.com

Living well with Lewy body dementia and comorbidities

Ken Clasper was diagnosed with young-onset Lewy body dementia 18 years ago. In his long running blog, he has shared his experiences, ideas and interesting links since 2012. See www.ken-kenc2.blogspot.co.uk

Dementia Diaries

This project has enabled 28 people with dementia from around the UK to record audio diaries, and you can listen to them or read a transcript. The thoughts and experiences shared here chart contributors' frustrations and opportunities that arise from living with many different forms of dementia. Listen and read at www.dementiadiaries.org

Alzheimer's Society blogs

Our blog website features updates on campaigns, research and other Society work, as well as personal stories from people affected by dementia – including the magazine's very own Life with Ma column. Read more at blog.alzheimers.org.uk

Let's talk about dementia

Alzheimer Scotland's popular blog involves many health and social care professionals and covers many aspects of dementia, with the aim of making sure that nobody faces the condition alone. See www.letstalkaboutdementia.wordpress.com

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

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

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

Side by Side Service User

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

Get in touch

0300 222 5706

volunteers@alzheimers.org.uk





Pam Roberts

Lancashire, aged 60 with Alzheimer's disease

What's changed most since your diagnosis?

I seem to have more confidence now in speaking out about my diagnosis, but less with finding my way about in the car and doing paperwork.

How has Alzheimer's Society helped you?

I did a 'Living well with dementia' course and go to an art group, both of which I have found helpful, but it's the staff that I find really encouraging and friendly. My daughter and I have set up a young-onset dementia café with their support.

What song or tune sums up your life so far?

The title of the Beatles' 'A hard day's night' strikes a chord, so to speak, as I cared for my mum-in-law and my late husband, who both had dementia. But I didn't know anything about Alzheimer's Society then.

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

To a family holiday in Florida about eight years ago. But my two granddaughters wouldn't have been born, so they would have to travel back with me! We had such a good time and all my family was there, we had lots of laughs.

What is your most treasured possession?

My wedding ring, because it reminds me of my late husband John. Unfortunately I have become allergic to it, so I have to wear it on a chain round my neck.

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.

For a few days, Ma returned to our house, which is where she spent her first years after her dementia diagnosis. Although we see her fairly often at her other son's house, where she now lives, we wondered how she would adapt to being back in her old room and what must seem only vaguely familiar surroundings.

Interestingly, her initial reaction before coming in was to seek reassurance from her granddaughter that this wasn't a permanent move back. She is certainly well settled where she is now and would not take kindly to being 'shared' between her two boys.

The visit was a success, partly because her granddaughter came with her and spent time with her. Although she struggled at times, she does also remember the house and, of course, us.

As ever, she impressed us with her ability to walk to the station and on to the art gallery in London, despite being a frail 92-year-old. She had much to say at the graffiti-inspired Basquiat exhibition at the Barbican. When a speaker mentioned that some people may not see this as art, Ma agreed in a loud voice that no, it certainly wasn't!

She loved having the family around the table at dinner and rediscovering parts of the house made more challenging by a new extension. 'I'm sure you had a white fridge?' 'What does that window look out on?' If she remembered her old room, faithfully preserved, she didn't say.

Dilly, a daughter-in-law

(continued next issue)



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



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

Talk to us

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

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

Talk to others

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

Visit alzheimers.org.uk/talkingpoint

Find the information you need

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

See alzheimers.org.uk/publications

Support near you

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

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

Carer

alzheimers.org.uk
[alzheimers.org.uk/facebook](https://www.facebook.com/alzheimers.org.uk)
[alzheimers.org.uk/twitter](https://twitter.com/alzheimers.org.uk)





People with dementia and carers try out reusable stickers for use as signs at home and elsewhere.

Self-adhesive signs



We visited the Co-production Group at Merton Dementia Hub in south London to get their opinions on two sets of self-adhesive dementia-friendly signs. The signs can be stuck onto most surfaces and are reusable.

One set of small-sized stickers is already available in our online shop, but we also took a larger set that is still in development. This means the group's feedback will be able to influence what the larger signs end up looking like.

Small stickers

The set of smaller stickers comes in a book, with 20 cupboard and drawer labels, 10 door labels and six coloured surrounds for light switches. Intended for home use, they include pictures depicting rooms and the contents of cupboards or drawers.

Myrtle said these labels would be useful at home, such as the one showing where cutlery is kept. Deirdre agreed, adding, 'Or showing where the socks are!'

Deirdre said the signs could be ideal for her and her husband, as they are moving house soon and will have to get used to a new layout.

Myrtle said she already made labels for things around the house, and Raksha asked whether the set could include blank stickers that people could write on. Jon, from our online shop, said we also stock Magic Whiteboard A4 sheets and an A5 Magic Notebook – these can be written on, erased and reused.

Peter thought the pictures on one of the kitchen cupboard stickers might not be obvious to everyone.

'The picture could be of something more instantly recognisable,' he said. 'Food like bread, fruit and vegetables rather than tins and other packaging.'

People with dementia agreed that some of the pictures could be improved. Ann said the showerhead image isn't clear, but adding water coming out of it might help.

Michael thought the image of cleaning products was too busy, with too many products in one picture. Ann wondered if a larger image of cleaning gloves would be more effective.

Sandra liked the utility cupboard picture, which features a vacuum

cleaner and ironing board. However, Brian questioned whether these would necessarily be in the same place, and Irene thought many people wouldn't be able to fit an ironing board into this kind of cupboard.

Bob could see the signs being useful for him and others in the group once their dementia becomes more advanced, adding, 'I don't feel we're there yet though.'

Large signs

The design of the larger signs is still being developed, and the group had a lot of helpful feedback about them.

Paschal wondered why the stickers need to be reusable, and Jon pointed out that many groups meet in venues owned by others, who might not want permanent signs.

Paschal said this could be useful in a local public library where a monthly dementia café is held. 'I end up somewhere different every time I come out of the toilet!'

Myrtle liked the size of the writing on the signs, especially as her husband's sight becomes more of an issue.

Two ideas had cost implications – Paschal asked if Braille could be included on them, and Peter said, 'Glow-in-the-dark signs would be useful at night, especially for the toilet sign. Perhaps for part of the sign if not possible for the whole image?'



Everyone agreed that the large signs would be useful in public venues, but not everyone thought they would use them at home.

Jacqueline said they need to look more like something you'd expect to see in someone's home so they wouldn't 'pick people out as different', and Margaret noted that different designs could suit different homes.

People tried taking the signs out of the pack, putting them up, peeling them off and replacing them onto the holding sheet. Margaret found this easy apart from putting the sticker back onto the right sheet.

'Having the name of the sign on the sheet would help to know where to replace it,' she said.

Raksha thought the signs could be useful for a weekend away. Deirdre agreed, 'The toilet sign would be very useful in a hotel room.'

The people with dementia found it more challenging to remove and replace the stickers, particularly having to hold the sheet down while peeling the sign off.

Sticking it back into the pack, Denise said, 'It's quite fiddly, but it's OK if it's not perfectly aligned.'

Although the group thought the high contrast colours made them clear, they preferred more neutral colours for some pictures and said red should be kept for signs that were instructions like 'way out'.

Cost and instructions

The set of small stickers costs £31.95 without VAT (you wouldn't need to pay VAT if buying them for a person with dementia). The large signs are being researched further before they become available, and the prices aren't yet known.

As is often the case with specially designed products, people thought the price seemed expensive. Jon assured everyone that our shop's prices are checked regularly against those elsewhere to ensure that they are competitive.

Group members thought the large signs' instruction sheet should be in a larger font, and this will also be fed back to the product's developers.

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



See p39 for a chance to win a set of small stickers.



‘My wife has vascular dementia, and I expect we’ll eventually need a smaller house closer to our son’s family. Should we move now or wait until we really have to?’

Moving home

After a dementia diagnosis, many people think about moving home when planning for the future. Moving home can have a big impact, and being concerned about how the person with dementia might cope with it is understandable.

Unfortunately, there is no simple answer to when you should do this. It depends on your individual situation, and you’ll need to balance the benefits, such as being closer to family, with any drawbacks.

Balancing

Generally, a person in the earlier stages of dementia is likely to cope better with moving home than someone in the later stages.

However, other aspects of your wife’s life could also make a difference. For example, has she been used to moving home often, or is it an unusual experience for her? Does she have many important memories associated with where you are now?

If you decide to move later on, when her dementia is more advanced, there are still things you could do to make it easier for her.

Preparing

With preparation, time and support, you could help your wife settle into a new home.

Keep the environment as familiar as possible by using furniture or decorations that she’s used to. This might include painting or changing the front door to match the old one.

Leaving the bathroom door open and a light on at night may help her get around a new layout, as could signage (see p30) and automatic sensor lights. Other technology, such as clocks that tell you whether it’s night or day, may help her orient herself. An occupational therapist should be able to advise on devices – ask your GP or local authority to be referred to one.

A person’s behaviour may become out of character as they get used to a new home, and it’s worth being prepared for this. Your wife might be more confused and disorientated, or she might seem less able to cope. There could be more distressing aspects to these changes, such as accusations or repetitive questioning.

Deciding

If the person with dementia isn’t able to make a decision for themselves about moving home, a decision will need to be made for them.

In England and Wales, this would usually be by an appointed attorney or deputy for health and welfare. If there is a financial element to the decision, an attorney or deputy for property and affairs would be involved.

In Northern Ireland, the decision would be made using a best interests decision-making approach, and any financial aspects would involve someone appointed through an enduring power of attorney.

Decisions made on a person’s behalf must be based on their best interests, taking into account their past or present opinions. It’s important to involve the person in the decision as much as possible.





Everyone in our online community, Talking Point, began as a new member – including our volunteers.

Warm welcomes

Whether it's you or someone else in your life who has been diagnosed with dementia, it is normal to feel overwhelmed and worried sometimes about what is to come. Remember that you are not alone and there are many people in similar situations who are keen to connect with each other.

Thousands of people dealing with all stages of dementia share experiences and support each other through our online community, Talking Point. It includes an area for people who have been recently diagnosed, and volunteers are always on hand to welcome new members.

All Talking Point volunteers started as members themselves, with their own questions and worries, and so understand what it's like not to know where to begin.

2am cuppa

One new member, whose husband had recently been diagnosed, browsed the forums for months before, in a moment of desperation at two in the morning, finally deciding to post a question. In the time it took her to make a cup of tea and return to her computer, she had pages of supportive replies from other members with ideas and tips based on their own experiences.

Another member dealing with his diagnosis felt empowered and more able to face the future after being able to identify with other people's fears.

Look around

Whatever you are going through, chances are there is someone on Talking Point who will understand. If you're unsure about joining, you can start by looking around the various forums and getting a feel of how members support each other.

After signing up, some people start by posting a message to introduce themselves in our welcome forum, which is specifically for new community members. Others prefer to browse the discussions for a while, reading what other members have written, before asking their own questions or replying to other people's posts.

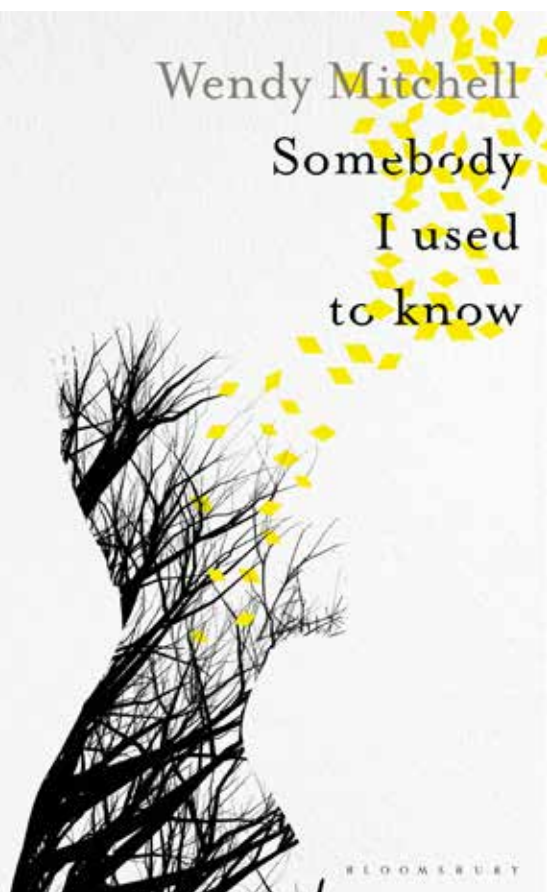


Join in

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

Readers' comments on a moving account of living with dementia.

Somebody I used to know



Somebody I used to know,
by Wendy Mitchell
(Bloomsbury, 2018),
320 pages,
£16.99,
ISBN: 9781408893364.

An audio version from Audible is also available, list price £14.99 – see www.amazon.co.uk

Wendy Mitchell, a Society Ambassador, has achieved a great deal of publicity for her book, which shares her experiences since being diagnosed with young-onset Alzheimer's in 2014.

Caroline Branney, Manager of our Dementia Knowledge Centre, recommends it not only for people interested in dementia, but also for anyone looking for a 'good read'.

'The story is written in a down to earth, entertaining style,' says Caroline.

'I couldn't put it down,' says PJ, a Talking Point member, even though she doesn't usually read books.

Ivor in Cumbria says the book showed him he's not alone in living with Alzheimer's. 'It's good to see her speaking out in print and on TV, putting dementia out in the open.'

Alan Rumary agrees, 'As someone with Alzheimer's, I have experienced so many of the things that Wendy describes. Although friends and family may think they know what Alzheimer's is like, they don't – they should read this book!'

Keith Oliver, another Society Ambassador living with Alzheimer's, helped us get the views of people with dementia involved in Kent's Forget Me Nots group.

'Seldom does a book inspire or move me in the way Wendy's did,' he says. 'The narrative is clear and crisp, and full of insight and wisdom.'

Practical advice

Chris Norris, a Forget Me Nots member, has read Wendy's book

twice already. In addition to identifying with her experiences, he also found her positivity and practicality inspiring.

'I could feel the sadness in the challenges, and the joy when she yet again found a way around what dementia placed in her way,' says Chris. 'Virtually every page had a golden nugget of advice around coping mechanisms.'

Carol Fordyce, also from the Forget Me Nots, adds, 'It is enlightening, empowering and gives others the strength to fight. It not only raises awareness, but in sharing her own ideas this also helps others to cope.'

Caroline says, 'Wendy covers everything from her own preconceptions when dementia was first mentioned, her thirst for more information and the way some friends went to ground, to when she fell off her bike, forgot her daughter's birthday and had to give up baking.'

Hillary Mead in Somerset, involved in the Society since its inception nearly 40 years ago, found many of the book's tips useful – such as labelling cupboards with photos of their contents and moving from novels to short stories and articles.

She adds, 'Wendy's book is written in such an informative, interesting, gutsy and heart-warming way, it holds the reader just having to read on.'

Elise Rendall in Kent says, 'A thought-provoking, inspiring and excellent read. It certainly deserves

its place on the bestseller list and I would thoroughly recommend it to others. Two of my family members have also asked to borrow the book, so Wendy's journey and story are certainly going to be shared more widely.'

Determination

Martin Taylor, from the Forget Me Nots, relates to Wendy's determination to understand what is happening to her.

'She has two supportive daughters, but lives alone and develops strategies for coping,' he says. 'Clearly, she has always been independent and well organised – an asset now, as are her impressive computer skills.'

He adds, 'I'm glad that my wife and I were able to listen to the book read aloud on Radio 4's Book of the Week. It gave us a lot to talk about.'

Martin's wife Sarah says the book should be required reading for everyone. She says, 'Wendy laments that so many people, including health professionals, simply "don't get it" and she has made it her life's work to inform and educate.'

Through flashbacks, which are italicised in the book, Wendy speaks directly to the person she was

before Alzheimer's – the 'somebody I used to know' in the title.

'Martin found the time switches a bit confusing when he heard it on the radio,' says Sarah. 'What they do is give the reader a picture of Wendy's past, right back to childhood visits to Blackpool with her mother.'

Janice Curtin in West Yorkshire says, 'I could recognise lots of the symptoms my husband is experiencing. This book takes you through the process of diagnosis and shows how positive steps can achieve a balanced life even with dementia in spite of out-dated attitudes of employers.'

One person's view

Of course, as a highly personal and individual account, Wendy's book cannot represent everyone's experiences.

Janice notes that it doesn't go far into the specific challenges faced by people in relationships, though she adds, 'Wendy's positivity and desire to fill her days with focus is heart-warming.'

Mervyn Brooks, another Forget Me Nots member, says Wendy has done 'a fantastic job', while underlining that everyone's experiences of dementia are

different and the need for diverse voices.

'I'd like to see somebody like a carpenter or bricklayer write a book about their dementia,' he says.

Caroline says, 'Not everyone can be as high profile as Wendy is, but we can all learn about the importance of positivity, reducing stigma, becoming a Dementia Friend and making our communities more dementia friendly.'

Insight and inspiration

Roy Jones in Somerset agrees, 'This book really captures the experience, triumphs and tribulations of someone trying to live well with dementia.'

'There is insight and inspiration for everyone, but I would especially recommend it to all professionals involved in working with people with dementia.'

Reinhard Guss, a consultant clinical psychologist and neuropsychologist in Kent, says, 'Of the messages that permeate Wendy's writing, my favourite has to be that "there is life, laughter and adventure" to be had after a dementia diagnosis. This has already proved helpful to people I meet in our memory clinic.'

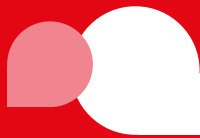
Your turn



For the next issue, we invite you to read *The Songminute Man*, by Simon McDermott (HQ, 2018), 256 pages, £16.99, ISBN: 9780008232627.

Let us know what you think by 7 May about this account of a father's life and the impact of his dementia 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 16 April quoting 'Song' for a chance to win one (see p39 for terms and conditions).



Talking Point members share tips about getting the best results when dealing with health and social care professionals.

Dealing with professionals

'Use a diary to log everything. Get full name and work pattern. Find out whether the professional is moving post in the near future, if they are then ask for someone else.' **Careroncoffee**

'Chase, chase and chase again. Don't be afraid to stand up for yourself. The squeaky door gets oiled first. If you don't stay on the ball, there is a high chance it will be dropped and things delayed. Write down when you spoke to someone so you don't forget outstanding matters.

'Whenever you speak to someone, be firm but polite. Don't swear, shout or be otherwise rude, even if you are angry about delays. Professionals are people too and will not bust a gut to help you if you don't stay civilised. Crying on the phone is acceptable though!'

Beate

'I just find the obvious approach of asking loads of questions and writing things down helps. Of course,

a sense of humour and the ability to accept teasing helps cover any embarrassment my other half has at me taking over doctor's appointments.

'Learning when to shut up and trust her to answer for herself is a work in progress as her dementia progresses. With social care professionals especially, care agencies sending emails always helps to create a paper trail, otherwise their internal communication lines can be a little lax sometimes.'

naesporran

'Make notes of ALL symptoms and concerns that you may have before any appointment, and take your notes with you to help ensure that nothing is missed.

'Take a notebook and pen with you so that you can note what is said. This is very important if bad news is a possibility, as once such news is given nothing more that is said may sink in and be remembered.'

karaokePete



Next issue

Do you have any advice about making a home dementia friendly? Email magazine@alzheimers.org.uk or write to the address on p3.

Computers and the internet

Some people with dementia will be used to using computers and mobile devices in their everyday lives, while others may be unfamiliar with them. Even for people who aren't confident using computers, a tablet with a touchscreen – such as an iPad – can be surprisingly easy to get used to.

Many activities can be enjoyed using apps on mobile devices or through websites. These include word puzzles, versions of board games, and games that include visual tasks, such as finding a set of objects within a picture. Some apps involve using your fingers on a touchscreen to 'paint' or do something similar.

The internet is a valuable resource for reminiscence and life history work, making it easier to find old photos of familiar places, pictures of someone's favourite things, as well as music and video.

Apps that use a device's camera to make video calls can be simple to use once set up, and can help the person stay in touch with family and friends.

Some people with dementia enjoy writing a blog (see p27) or using social media, such as Twitter, to share experiences and ideas.

With all of these activities it's worth remembering that, for most people, the technology is not the point – using a computer and the internet simply provides more ways to do them.

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

Keep track of home visits from health professionals

My visitors book can help you keep note of the health professionals who visit you at home.

You can record what happened during the visit as well as when the next appointment is.



To order call
0300 303 5933 or email
orders@alzheimers.org.uk
and quote code 923.



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Reusable signage

One lucky winner, drawn from correct entries received by 7 May, will win a set of reusable signage stickers, and five runners-up will get a key fob designed by the same company, Find.

Q: In 1389, all pubs in England were required to hang signs outside their premises to make it easier for:

- A. Signwriters to get work.**
- B. Passing inspectors to check the quality of ale.**
- C. Richard II to find the nearest pub.**



Cupcake Day apron

We have three Cupcake Day aprons for three lucky winners drawn from correct entries received by 7 May, in time for Cupcake Day on 14 June.

Q: In the US, icing on cakes is often called:

- A. Frosting.**
- B. Snowing.**
- C. Sugary cake decoration paste.**

Send us your competition answers for us to receive by 7 May, 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.

Fiddle muff competition

A fiddle muff was won by J Baxi in Warwickshire and S Haydon in Kent. Answer: The phrase 'To fiddle while Rome burns' refers to a story about Roman Emperor Nero playing the lyre while his city was burning.

Book giveaway

The five readers who each won a copy of *Somebody I used to know* by Wendy Mitchell were H Mead and R Jones in Somerset, E Rendall in Kent, M Hill in Tyne and Wear, and J Statman in Greater London.



CALLING ALL BAKING PROS, RECIPE REBELS AND FIRST-TIMERS

Rise against dementia this Cupcake Day, on 14 June
Sign up for your free fundraising kit today

cupcakeday.org.uk



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**Cupcake
Day**