

Dementia together

August/September 2018
Alzheimer's Society's magazine

Truth will out
Frontotemporal awareness

Caring together
Hospice and mental health



Play to win
Drama group

Also in this issue
Dementia Connect
Memory Walk
Reminders
Safeguarding concerns



Role reversal
Facing change



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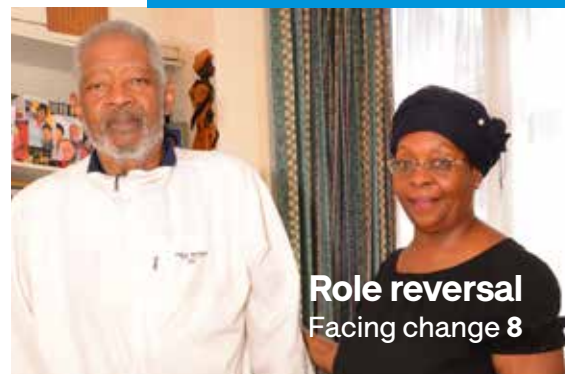
New Deal for Dementia 4

If you're a fundraiser, activist, volunteer or Dementia Friend, or if you have a diagnosis or are a carer or former carer, then this magazine is for you. We share real-life stories and inspiring ideas that you can use to improve your own and other people's experiences of dementia.

As Memory Walk approaches this autumn, we hear from a walker who's encouraging others to get involved in this fantastic event (see p13).

In the meantime, do you know anyone else who could benefit from this magazine, whether because they're involved in the dementia movement or are affected by the condition themselves? If so, make sure they know how to subscribe (see below).

Danny Ratnaik, Magazine Editor



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

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Magazine Editor, Alzheimer's Society,

43-44 Crutched Friars, London EC3N 2AE

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Social care: Action now

Alzheimer's Society has called on the government to prioritise social care reform after its long-awaited proposals were pushed back.

A green paper setting out proposals for the future of adult social care in England has been delayed until the autumn, when the government said new NHS plans would also be ready.

Jeremy Hughes, our Chief Executive Officer, said, 'Hundreds of thousands of people with dementia rely on social care every day, and each day we wait for reform leaves them enduring inadequate care and crippling costs.'

'The green paper is an opportunity to end this injustice, so I sincerely hope this delay means the government is taking the time to get it right, not pushing it down the list.'

'We can't accept a promise of reform sometime in the future – we need action now. The government must deliver high quality social care to everyone who needs it, at a fair price.'

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

New Deal on Dementia: Transforming lives

We are continuing to develop our ambitious five-year strategy, the New Deal on Dementia, which launched in April 2017. Its three pillars – focusing on support, society and research – will create much-needed change for everyone affected by the condition.

Through our New Deal on Support, we want everyone affected by dementia to get the information, advice and support they need, as and when they need it. A core element of this is Dementia Connect, the new service we are developing that combines face-to-face support with telephone and online advice.

Our New Deal on Society is campaigning for the rights of people affected by dementia, helping create communities where they are supported and accepted. The number of Dementia Friends recently passed an incredible 2.5 million, and our campaigns are putting ever more pressure on government for real change.

At the same time, our New Deal on Research is building a bigger, better-funded national and international network of researchers to improve care today and unlock the answers for a cure tomorrow. The new UK Dementia Research Institute is a key part of this, and its first labs are now up and running.

'We will transform the landscape of dementia forever,' said Jeremy Hughes, our Chief Executive Officer. 'Until we find a cure, we will strive to create a society where those affected by dementia are supported and accepted, able to live in their community without fear or prejudice.'

See page 12 for more about how our new Dementia Connect service is developing.

Gas cookers: Free safety valve

Locking valves for gas cookers that prevent leaks and fires are now available free for people with dementia in England and Wales (also Scotland). **For more information from gas network company SGN, visit www.sgn.co.uk/lcv or call 0800 975 1818 (free).**

NHS checks include dementia

Alzheimer's Society has helped ensure that free NHS Health Checks for people aged 40 and over in England will now include advice on reducing your risk of developing dementia.

GPs and other health professionals will tell people about the importance of keeping mentally and physically active, stopping smoking and maintaining their social life. Previously this was only provided to people aged over 65.

Last year, a pilot project led by the Society, Alzheimer's Research UK and Public Health England found that this can be an effective way to encourage people in midlife to make positive lifestyle changes to reduce their risk of dementia.

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



Cupcake Day: A million thank yous!

More than 30,000 supporters across the country have raised over £1 million – and counting – by baking, buying and sharing cakes for this year's Cupcake Day.

Candice Brown (pictured above), winner of The Great British Bake Off, hosted a pop-up event on London's South Bank as part of our first ever Cupcake tour, which also visited Birmingham and Newcastle.

Inspired by Dame Barbara Windsor, who revealed she has Alzheimer's earlier this year, the cast and crew of EastEnders held a Cupcake Day on set. Other celebrities backing the event included writer, actor and Society Ambassador Meera Syal and celebrity chef Paul Hollywood.

As funds from the event continue to come in we have already beaten last year's total – a huge thank you to everyone who took part!

Wintry winner

A snowy scene from a supporter in Dorset will feature on an exclusive Alzheimer's Society Christmas card this year. Our competition was won by Kathleen Davidge's evocative photo of a friend walking sheep up a country lane in Chickerell, near Weymouth.

Buy Kathleen's card from late August at shop.alzheimers.org.uk



Do you want to meet new people, keep in shape and fight dementia? This autumn, Alzheimer's Society can help on all three fronts.

Most charity fundraising events are simply what they say – ways of raising money – and many also require great strength and fitness.

Memory Walk is different. Of course, we want to raise lots of money for better support, to create real change and fund cutting-edge research. But Memory Walk is about so much more than fundraising, and you don't have to be super-fit to participate.

Memory Walk is for everyone. Supporters of all ages, including many people with dementia, take part in walks each year. For both people walking and the many volunteers who make the walks possible, there is always a wonderful atmosphere as we unite to take on dementia together.

Walking together is also a great reminder that keeping as active and involved as possible not only helps to reduce your risk of dementia, but is also an important part of living well with the condition.

Read about how important Memory Walk has been to Claire and her family on p 13, and I hope we'll see you at one of our many walks this year. Find your nearest at memorywalk.org.uk or call 0300 330 5452 (local rate).

Jeremy Hughes
Chief Executive Officer



In the press

Herpes virus link?

The idea that infections might trigger the onset of Alzheimer's has been around since the 1990s. The theory gained momentum recently after the publication of two research papers. Herpes virus – commonly associated with cold sore infections – was detected at greater levels in the brains of people who had signs of Alzheimer's than those who didn't. You might have seen coverage of this story in The Times, The Telegraph and The Guardian.

The new research suggests that amyloid – one of the toxic proteins that builds up in the brains of people with Alzheimer's – might accumulate around viruses to ensnare them and stop them causing further damage.

What isn't yet clear is what causes the build up of amyloid to get out of control, which happens in Alzheimer's disease. Joel Dudley, who led some of the research, believes that the herpes virus 'puts gas on the flame', making Alzheimer's progress faster than it would have otherwise. However, there isn't good evidence that herpes may actually cause Alzheimer's.

James Pickett, our Head of Research, said, 'While this is robust research, it could not prove that the viruses were actually responsible for Alzheimer's disease. It doesn't change what we already know about the causes of dementia. Having cold sores won't put you at increased risk of developing it and people shouldn't be unduly worried.'



World Alzheimer's Ball

Our second World Alzheimer's Ball has raised over £200,000 for the fight against dementia.

Starting with simultaneous dinners at a number of ambassador's residences and embassies across London, the annual event culminated in a ball for 250 guests at Lancaster House, hosted by Society Ambassador Angela Rippon.

Attendees pledged £60,000 after hearing an inspiring speech from Dr Avril Staunton (pictured with Jeremy Hughes, Avril's husband Michael and Angela) about her personal experience of living with young-onset dementia. Further funds were raised through ticket sales and a silent auction.

Iceland unites against dementia

Supermarket chain Iceland is once again raising money for us during its Charity Week.

Iceland employees are taking on fundraising challenges from 11–17 August, and hundreds of volunteers will hold bucket collections across the country, so look out for them at your local store.

Last year's Charity Week raised £600,000 for both the Society and Alzheimer Scotland, and this year we hope for even more to fund vital care and research.

Iceland founder Sir Malcolm Walker was recently named as one of our newest ambassadors, along with actor Vicky McClure, former government Minister Hazel Blears, former banking executive Kamel Hothi, investment banker Rupert Adams, hotelier Laurence Geller and insurance chief Chris Wallace.



Dementia Friendly Awards

Who will you nominate for this year's Dementia Friendly Awards?

Nominations are open to recognise and celebrate individuals, organisations and communities who are leading and inspiring a change that will transform the lives of people with dementia forever.

Categories include three new awards – Trailblazer of the Year, Youth Organisation of the Year and a Championing Diversity award.

The Dementia Friendly Awards for Northern Ireland will take place in Belfast on 20 November, while the England and Wales award ceremony will be in London two days later.

Nominate by 20 August at alzheimers.org.uk/dementiafriendlyawards

Carols at Christmas 2018

Alzheimer's Society's Carols at Christmas concerts will be held at 11 locations across the UK, including St Paul's Cathedral.

Around 2,400 supporters are expected to unite at the iconic London landmark on 18 December for an evening of spectacular festive entertainment. There will be live music, carols, celebrity festive readings and a performance from one of our Singing for the Brain groups.

Other concerts will be held in cities including Manchester, Birmingham and Belfast.

To be the first to hear more about our Carols at Christmas concerts, register your interest at alzheimers.org.uk/carolsatchristmas

Older LGBT+ care standard

Health and social care organisations providing good quality care and support to older LGBT+ (lesbian, gay, bisexual and trans) people are to be recognised.

Developed by LGBT+ information and support provider Opening Doors London, the Pride in Care Quality Standard will be awarded to those who show LGBT+ inclusive practice in customer service, safety and security, policy and procedures, publicity and promotion, and recruitment and training.

Opening Doors London has also developed training courses to enable health and social care professionals to provide more personalised care and support to older LGBT+ people.

To find out more, email prideincare@openingdoorslondon.org.uk or call 020 7239 0400.

PIP review

Some people with dementia who claim Personal independence payment (PIP) – for people aged under 65 who have extra care or mobility needs – may be entitled to additional support.

Last year, the High Court ruled that aspects of the government's PIP policy discriminated against people with certain needs, including some people with dementia.

If you claimed PIP on or after 28 November 2016 and receive only the standard mobility component or no mobility component, then the government will automatically review your claim without further face-to-face assessment.

If you started claiming PIP before 28 November 2016 and you receive only the standard mobility component or no mobility component, then you are entitled to make a new claim. However, your PIP could go up or down based on the new assessment, so you should speak to a benefits adviser, such as at Age UK or Citizens Advice, beforehand.

In briefs

2.5 million Dementia Friends

Over 2.5 million people are now Dementia Friends! Already the biggest ever initiative to change people's perceptions of dementia, now more of you than ever before are helping to transform the way the nation thinks, acts and talks about the condition.

See dementiafriends.org.uk to find out more.

WHO commits to dementia

Alzheimer's Society has helped influence the inclusion of dementia in the five-year strategic plan of the World Health Organization (WHO) for the first time.

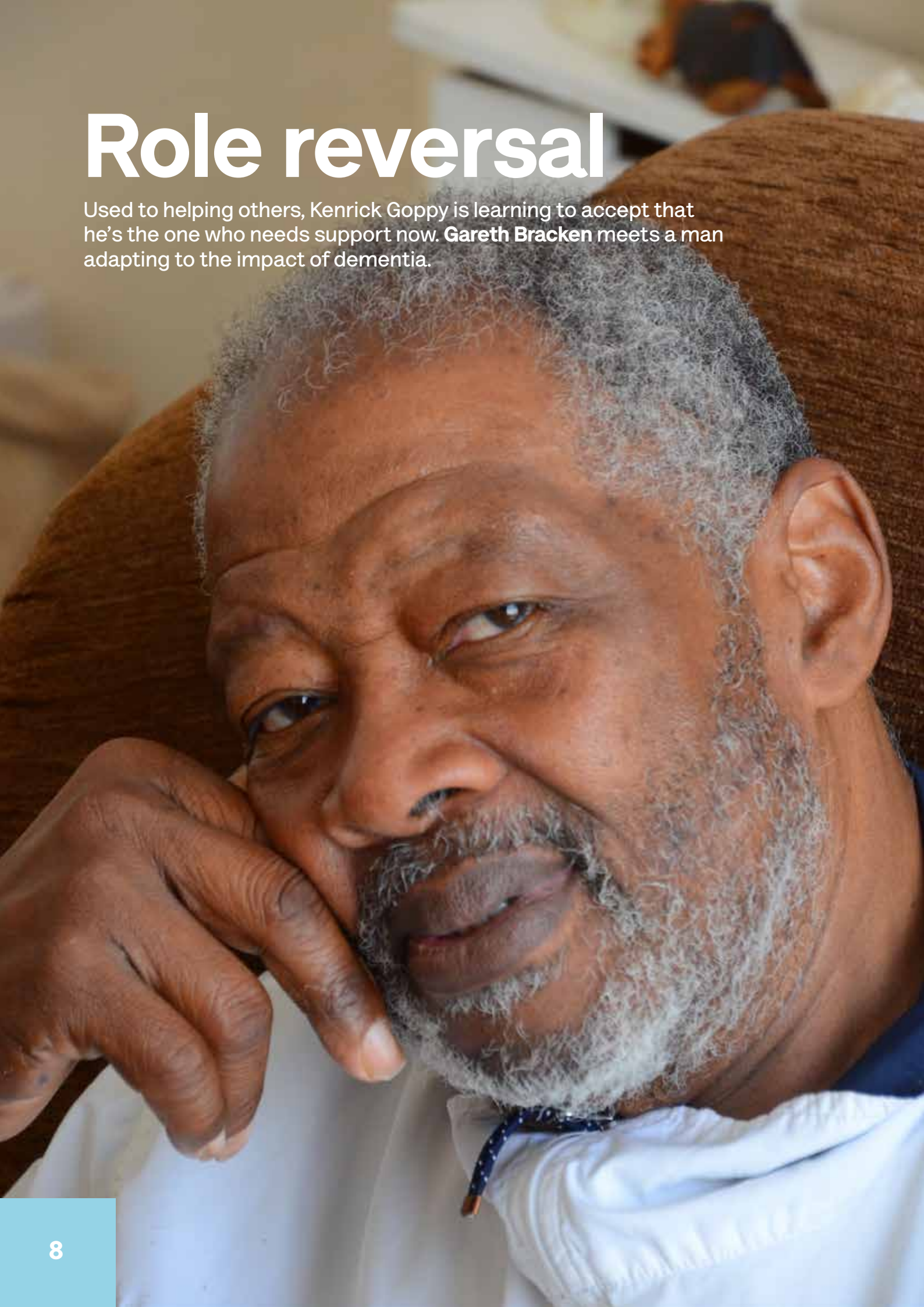
After an initial draft failed to mention dementia, we worked with Alzheimer's Disease International, the Department of Health and Social Care, the UK government's Chief Medical Adviser and a number of other countries to call for its inclusion. Alongside the WHO Global Action Plan on Dementia, this will promote dementia as a global health priority.

Hospital visits victory

John's Campaign, supported by Alzheimer's Society, has succeeded in getting all NHS acute trusts in England to pledge to offer unrestricted hospital visiting hours for carers of people with dementia. The campaign was set up by Nicci Gerrard after her father, Dr John Gerrard, who had dementia, endured a catastrophic stay in hospital.

Role reversal

Used to helping others, Kenrick Gopy is learning to accept that he's the one who needs support now. **Gareth Bracken** meets a man adapting to the impact of dementia.



‘In many respects, life is rich,’ says an upbeat Kenrick Goppy, sharing insights and anecdotes about his work, family and philosophy.

However, since he developed dementia, Kenrick’s optimistic outlook – although genuine – overlays a real struggle to remain the man he used to be.

Family network

Kenrick, 73, grew up in Guyana, a Caribbean nation on the South American mainland.

‘Life there was fairly good,’ he says. ‘If you’re making an English comparison, it was like being middle class.’

Kenrick’s grandmother came from what he describes as an influential family. Her eldest brother, Kenrick’s Uncle Charlie, was a sea captain who is the first African Caribbean person recorded as having skippered a ship through the English Channel.

In his early years, Kenrick spent a lot of time with his aunt and grandmother while his mother was at work.

‘The older generation always wanted to have the grandchildren around them,’ he says. ‘In that respect I was mothered and double mothered!’

Kenrick moved to England in the early 1960s in his mid-teens, joining relatives who were already in London.

‘Those early days were quite exciting – there was a family network,’ he says.

Kenrick was a keen boxer and gymnast, although he had to give these up after starting A-Levels.

‘I was studying and also working to pay my way, meaning there was competition for my time,’ he says.

‘I’d go straight from college to do an evening shift at the post office, go to bed around midnight and get up at 6 or 7 in the morning to get out again.’

Direct approach

He became involved in community youth work, setting up Saturday schools in local churches and teaching boxing and gymnastics.

‘We started to find the failure of young African Caribbean kids, particularly boys, in the school system,’ he says.

‘We felt the education system didn’t have any time for them, so we set up supplementary schools in order to bring some discipline.’

Kenrick was also part of the British Black Panthers, who fought for the rights of black people and other people of colour.

‘The young generation were critical, to some extent, of the Martin Luther King approach, so we chose something much more direct,’ he says.

‘Rather than asking for mercy, you organise yourself and create some of the resources that you need in order to advance yourself, such as the supplementary schools.’

Kenrick has a degree in economics but forged a career in social work, as social services were keen to utilise his connections with young people in the local area.

He spent the majority of his career working for social services in Brent, in north-west London. He focused mostly on mental health and young people, before taking early retirement in the early 2000s.

Kenrick married Herma in the early 1970s, and they now have three sons and seven grandchildren.

Keeping alive

It was in 2014 that Herma first noticed that Kenrick, ordinarily very active and articulate, didn’t seem as mentally sharp as usual. However, she assumed it was just a case of him getting older. Looking back, she feels that her husband became very good at covering up any issues he was having.

Kenrick admits going through a period of denial, and describes the pressure he puts on himself to carry on as normally as possible, to avoid people realising how difficult he might be finding things.

‘Because of how I lived in the community, I’m always having people asking me a question or asking for advice,’ he says.

‘Sometimes I recognise the face but I can’t remember the name. Or I remember the name but can’t remember where they came from. How do you explain that to them?’

Quick read

A social worker who helped others for decades, Kenrick Goppy has now found himself as the person in need of support.

Kenrick, 73, has Alzheimer’s, which can make it difficult for him when approached by his local community for advice.

However, these connections help him to feel alive, along with the strong support of his family.

Kenrick also has diabetes, but says that his dementia causes him more anxiety in his quieter moments.

‘I know my community – don’t tell them “no”, because the first thing they’ll say is, “Now you’ve retired and got a pension you no longer care about us” – they’re sensitive.

‘So if you know that’s going to happen, you’re going to have to try your best.’

Kenrick may explain to people that he has Alzheimer’s, but he says many aren’t able to accept that someone like him could be so badly affected by it.

That said, he still draws positives from these situations.

‘When someone you haven’t spoken to for three or four years phones you up, you’re trying to work out the image of what they were like the last time, which helps to keep me more mentally fluid,’ he says.

‘And even if I can’t help I can sometimes counsel, which is actually quite rewarding.

‘It keeps me involved – actually it keeps me alive.’

Greater anxiety

After his symptoms became impossible to ignore, Kenrick sought medical help and was diagnosed with Alzheimer’s in December 2014.

He feels that some older members of the African Caribbean community see dementia in a religious rather than medical context.

‘They’re in a state of denial and don’t want to accept that it is a natural disease,’ he says.

‘They’ll say, “Dementia is because you didn’t go to church, you didn’t say the Lord’s prayer – it is a punishment of God.”

‘But I think it’s opening up. The younger generation is not so much tied to the superstitions of the old.’

Despite coming across as a jovial figure with a broadly positive outlook, Kenrick does admit to having private concerns about his dementia.

‘The image I market is not 100% of what I feel,’ he says.

‘I have a greater anxiety level when I’m quiet, particularly when it dawns on me that I’d planned to do something that then went out of my mind.

‘Herma may mention it casually and I say to her, “By God, it’s gone.”’

Kenrick also has diabetes and has had three stents in his heart as a result of angina.

However it is dementia that worries him most, as he fears it affecting some of his key characteristics.

‘Feeling that I might not be able to express myself in the way or the language that I want because of the anxieties I have – it does shake you up a bit,’ he says.

Straightforward support

As a result of sepsis, Kenrick now walks with the aid of a frame. He has also stopped driving and his lack of mobility and freedom, along with the dementia, have caused a downturn in his motivation.

His wife and sons do their best to help him remain active and involved, meaning Kenrick is usually out of the house three or four times a week attending various groups. This includes the dementia café run by community resource centre Ashford Place, and two groups at Willesden City Mission.

Kenrick and Herma also attend lectures and concerts, while their grandchildren often visit at weekends.

Kenrick says it’s difficult for his sons to accept that he is declining mentally, and he thinks they can be over-protective at times. However, he remains grateful for their involvement.

‘There’s supportive indulgent and there’s supportive directive, and I think my family have been much more directive than indulgent,’ he says.

‘They’re straightforward and up front, and that has been beneficial.’

Having always been someone who helped others with their problems, Kenrick has had to acknowledge that he is now the one in need of assistance.

‘You get to a point where you have to accept that you need support – you’re not only a provider of it,’ he says.

Next steps

- To hear Kenrick’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/getsupport



Keeping connected

Dementia Connect is a new service we're developing to keep in touch with people affected by dementia and to help them get the right support at the right time.

As part of our current strategy – the New Deal on Dementia – by the year 2022, we want to be there for everyone affected by the condition to offer information, advice and support.

We're introducing a new service called Dementia Connect to cut through the confusion and delay that people often face in finding the right local support.

Dementia Connect combines face-to-face support with telephone and online advice, so people can get the help that they need, when they need it. To make sure we're developing it in the right ways, the service is being adopted in a couple of areas initially.

The first is Pennine Lancashire, which includes Burnley, Hyndburn, Pendle, Ribble Valley and Rossendale. Here, specialist dementia advisers are assessing and addressing the needs of people who either contact us themselves or who are referred to us.

This begins with an initial phone call, which can lead to face-to-face visits or connections to other services as and when required. There are also 'keeping in touch' calls, where we contact people after an agreed amount of time to see how they're getting on.

Here for all

'We're still here to provide specialist advice and support, but it's more streamlined and person-centred now,' says Sarah Bowron, a Dementia Adviser near Burnley.

'Some people want support early on, while others need the bigger picture – information about what might happen in future. We're here for both, we're here. They already know who we are and the relationship is there. It's just keeping that connection with people.'

In December 2016, Adrian Ferguson's mother-in-law, Eileen, was diagnosed with mixed dementia – vascular dementia and Alzheimer's disease – and his father-in-law, George, with Alzheimer's.

'We just sat in a room with the psychiatrist, got given a handful of leaflets and basically got told, "You're poorly – bye,"' he says.

After contacting us, Adrian was visited at home by Sarah, who came with a list of the obligations that social services had to the family and some valuable advice.

'It was just a relief to talk to someone who understood what we were going through,' says Adrian.

'My wife and I used to get frustrated but we've never fallen out with them – that's from Sarah.'

Sarah has also supported Adrian and his wife on the phone during difficult times, like when George was in hospital.

'We would have been in dire straits without Alzheimer's Society,' says Adrian.

Someone there

Katherine Donnelly, now 66, was diagnosed with early-onset Alzheimer's in September 2016.

'From the day of diagnosis, there was someone there,' she says.

Katherine and her husband, Matt, have received both phone and face-to-face support that has armed them with new knowledge.

'We've now done a power of attorney, which we wouldn't have known about,' she says.

'There was also information about making your home dementia friendly, which will be useful in future.'

Dementia Connect has ensured the couple don't feel isolated or alone.

'It's just knowing there is someone out there who you can talk to who understands,' says Katherine.

'My philosophy from day one has been positivity and determination to live well with dementia, so this has been really helpful for me.'



Photographs: Mike Frisbee



This new service isn't available nationally yet – to find support near you from Alzheimer's Society and others, visit alzheimers.org.uk/getsupport



Go ahead

A Dementia Friend is starring in our TV ads for Memory Walk to encourage others to experience this enjoyable and fulfilling event.

Claire's family began taking part in Memory Walk after her mother's diagnosis in 2013, and the impact of her first walk has stayed with her. 'I felt isolated because dementia isn't talked about like cancer or heart disease,' she says. 'But joining Memory Walk, you feel you're not on your own.'

Every autumn, thousands of people unite at Memory Walks all over Wales, England and Northern Ireland. As well as raising millions for research and support, it's a great way to come together for the cause.

'I wasn't really sure what to expect,' says Claire, now 44 and a Dementia Friend. 'But I walked into a very positive, happy and upbeat atmosphere, which was amazing.'

Really important

Claire's mum, Gill, lives in south Wales and was 69 when she was diagnosed with Alzheimer's, though this was later changed to mixed dementia – Alzheimer's and vascular dementia.

Living in London, Claire had noticed a change in her mum over the phone before it became clear she was withdrawing from conversations and daily activities. Gill didn't get any follow-up in the year following her diagnosis at the memory clinic. However after Claire's dad, John, contacted Alzheimer's Society, they went to Singing for the Brain, a dementia café and a day centre.

Gill and John joined Swansea's Memory Walks for two years in a row, and both Claire and her sister have taken part in others.

'It's been really important to us as a family,' says Claire.

TV star

Keen to get others involved, Claire is starring in our TV ads for Memory Walk. She says filming the ad was great fun. 'It just felt like a fun day with friends.'

Using her phone, Claire showed the ad to Gill, who has been in residential care for a year and now only says the occasional word.

'Mum has barely spoken on the last few visits, there's very little interaction or recognition.

'She was intently looking at the screen. I showed her the ad a second time, and she was taking it in even more.

'I asked her if she liked it and she said, "Yes." It was like her endorsing it for me, like she was saying, "Go ahead."'

Find your nearest Memory Walk – visit memorywalk.org.uk or call 0300 330 5452 (local rate).

Think active



Keep your brain active while fighting dementia by setting up a regular Brain Gym gift – sign up today for just £5 and you'll receive monthly puzzles in the post to give your brain a regular workout. See alzheimers.org.uk/brain-gym or call 0330 333 0804 (local rate).

Become a champion

Dementia Friends Champions give others the information and encouragement they need to make a positive difference for people affected by dementia in their community. Champions attend an induction and get support when they need it to help create dementia-friendly communities everywhere.

Find out more at dementiafriends.org.uk



Shop for us



You can raise money while shopping online thanks to AmazonSmile – select Alzheimer's Society as your chosen charity and 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.

Golfing to feel good

A Dementia Friends Champion in East Yorkshire is finding out just how much you can benefit from being a Side by Side volunteer.

Annette Jackson, a retired teacher, didn't appreciate what she had to gain when she first volunteered for Side by Side in Hull and East Riding. However, her regular games of golf with John Jones over the past year and a half have been a revelation.

'When I started volunteering, I wanted to do something for others,' says Annette, aged 56. 'But golfing with John makes me feel good.'

'When I arrive to pick John up and say do you know me, he sometimes jokes – he has a fantastic sense of humour – "Of course I do, George!" But the most heart-warming was when he said, "Here she comes, my guardian angel."'

Not looked back

Through Side by Side, volunteers support people with dementia to carry on doing the things they enjoy. This could be anything from Scrabble to snowboarding, but it was golf that brought Annette and John together.

'My daughter-in-law, Lottie, was about to sign up to Side by Side when they asked her if she played golf,' recalls Annette. 'She said she didn't, but knew someone who did.'

'Lottie had to return home for photo ID, and they jokingly said, "When you come back, will you bring your mother-in-law?" Well she did, and I've not looked back!'

Joy of playing

John, now 80, was diagnosed with Alzheimer's in 2015. Even with the support of his wife Eileen and their family, he was becoming increasingly withdrawn. He even stopped playing golf, the 'second love of his life' after Eileen.

Despite this, he had Annette practising her golf swing in the living room the first time they met.

'He enjoys the golf very much,' says Annette, 'but also the pint in the clubhouse, where he chats to the staff. They show a real interest in him, especially when he tells his stories about Hull docks, where he used to fillet fish when he was a young man.'

'On our way home, John will repeatedly thank me and ask if we can do it again and how we go about arranging it. He might not be able to remember what his score was or how he played, but he certainly remembers the joy of playing and the fun we have.'

Good humour

As a Dementia Friends Champion, Annette delivers information sessions everywhere from secondary schools to the Women's Institute. She also now runs them with new Side by Side volunteers. Yet not much can beat her time spent with John.

'He always makes me laugh with his good humour,' she says. 'We chat about things he has done in the past, his army days and Hull dock days, his family and particularly his wife Eileen. I always look forward to golfing with him.'



See if Side by Side is available near you at alzheimers.org.uk/sidebyside
Call 0300 222 5706 (local rate) or email volunteers@alzheimers.org.uk to find out more about volunteering.



Dementia-friendly parliament

Ele Yorke, in our Public Affairs and Campaigns team, reports on work to change attitudes at the highest levels of government.

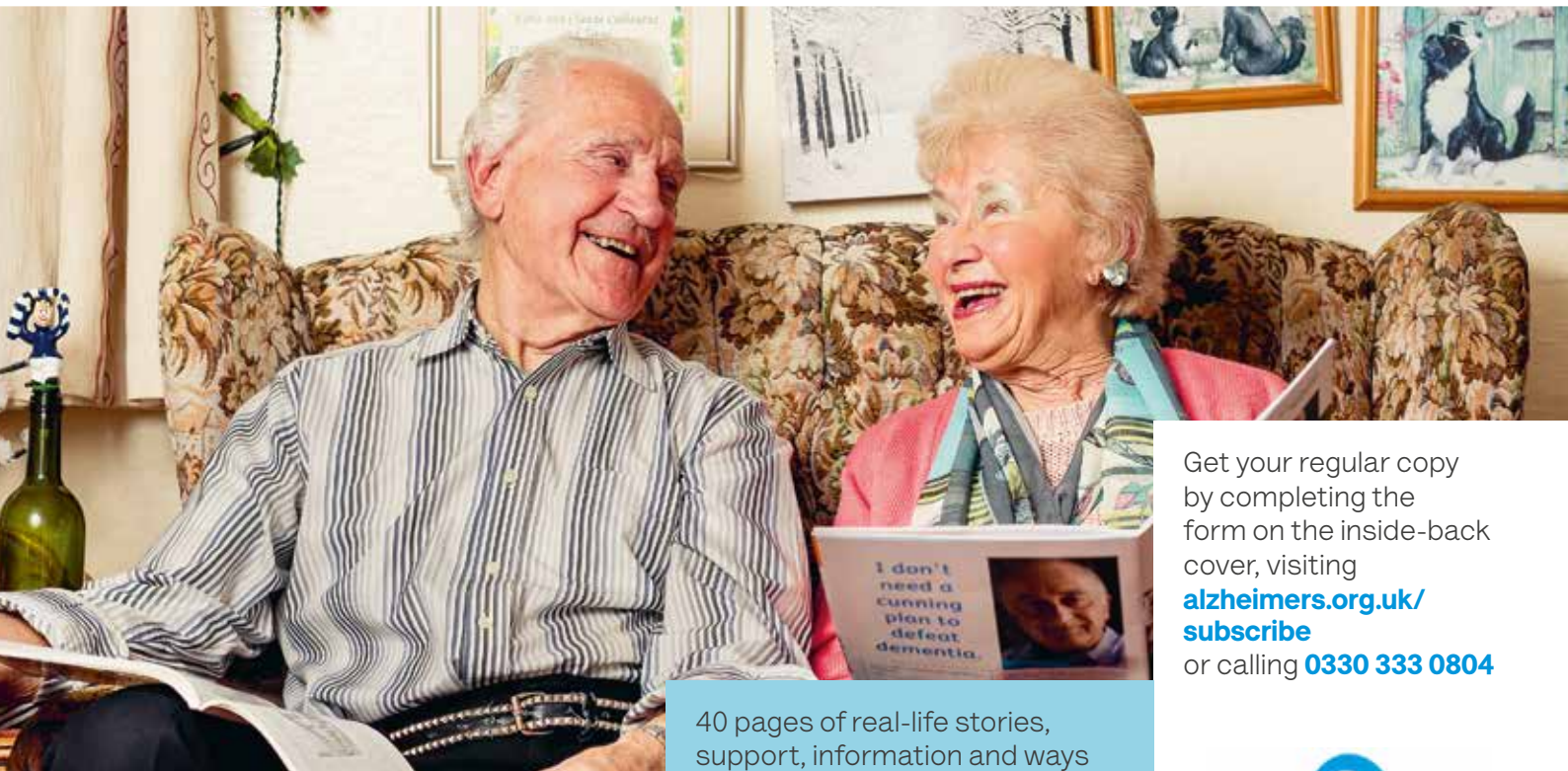
The way that social care is provided and paid for is extremely unfair for people affected by dementia. The government's promise to get people's opinions about a new social care system is one opportunity for us to address this.

We're making the voices of people with dementia and carers heard across UK government. However, we're also challenging politicians and civil servants to recognise that making a real difference involves everyone on a more personal level – including them.

Our Dementia Friendly Parliament project is helping Westminster work towards becoming the first dementia-friendly parliament in the world. We want all MPs, Peers, parliamentary staff and civil servants to become Dementia Friends. We also want all parliamentary buildings to be accessible and welcoming to people with dementia.

We've held Dementia Friends information sessions with the Cabinet and with ministerial teams at various departments. We've also signed up Shadow Cabinet members as Dementia Friends, as well as many other MPs and their staff. This means that people at the highest levels of government are getting a better understanding of dementia and what needs to change.

We believe that parliament is an important place to start in creating a dementia-friendly society. If Dementia Friends in parliament and government are considering people affected by dementia, this will be an excellent first step in ending the injustices that people face on daily basis.



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

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

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

**Subscribe to
Dementia together
magazine today**





Hurling friends

Ballygalget GAC has become the first Gaelic Athletic Association club in Northern Ireland to register to become dementia friendly, the first initiative of its newly opened health and wellbeing centre.

The club, whose teams play hurling and camogie (a similar women's game), started by hosting two-hour Dementia Friendly Communities awareness workshops, where local community members found out more about dementia and how best to support people affected by it.

'For people living in a rural area, it can be difficult to know where to turn for support,' said Roisin Coulter, North Down and Ards Dementia Support Worker.

'By working to become dementia friendly, Ballygalget GAC are making dementia one of their priorities and showing their support to people living with and affected by dementia within their club, parish and wider community.'



Yn Gymraeg

A Welsh-language focus group – believed to be the first of its kind – has met to share experiences and improve the support received by people affected by dementia whose first language is Welsh.

Alzheimer's Society Cymru held the group in partnership with the Welsh Language Commissioner's Office. Group members raised issues including the use of inappropriate tests to help diagnose dementia and monitor its progress, despite the existence of validated Welsh-language versions. People also spoke about a reluctance to insist on the Welsh-language support that they need – even though they have a right to this – and a lack of Welsh speakers among service staff.

Hayley Hogan, our Engagement and Participation Officer for Wales, said, 'The group enjoyed the opportunity to communicate in their first language and to influence change across the dementia community.'

Champion award



Gina Awad, a Dementia Friends Champion in Exeter, has been recognised in the Queen's Birthday Honours List and will receive a British Empire Medal (BEM) this autumn.

Gina has created 1,654 Dementia Friends by holding 111 information sessions since 2014, and founded her local dementia action alliance, which involves over 60 organisations. She also inspired a practical resource that Devon GPs have been using to become dementia friendly, and hosts Living Better with Dementia, a quarterly radio show on local station Phonic FM.

Fellow local activist Nicky Baker, who has experienced dementia with both of her parents, said, 'It has been through Gina's dogged determination and unfailing commitment with spearheading Exeter Dementia Action Alliance that there has been a significant shift in attitudes in Exeter and its environs.'



Bringing Brent together

An alliance in north-west London has announced its vision for Brent to become the country's first dementia-friendly borough. Community Action on Dementia Brent (CAD-Brent) is bringing local organisations together with the council to raise awareness and make more support available.

Spearheaded by campaigner Dianne Campbell (pictured), who has vascular dementia, one goal is to increase the number of dementia cafés across the borough from eight to 20.

Danny Maher, Chief Executive Officer of Ashford Place Community Centre and Chair of CAD-Brent, said, 'People living with dementia tell us that they want to stay in control of their lives, that dementia doesn't mean they cannot continue leading positive productive lives and that they need the wider community to be understanding and enabling.'

Become a Dementia Friend

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



Visit dementiafriends.org.uk
to find out more

Truth will out



Quick read

Liz Lane, whose husband Antony has frontotemporal dementia (FTD), wants to raise awareness of this rarer form of dementia.

Antony has the behavioural variant of FTD, which caused him to show a lack of empathy and behave inappropriately in social situations.

Liz found a lack of FTD awareness among health professionals and received criticism from former friends who don't understand the condition.

Determined to spread the word about FTD, Liz is set to step up her efforts to get her message out.

Having fought for her husband's diagnosis amid criticism and disbelief, Liz Lane wants everyone to understand the truth about frontotemporal dementia. **Gareth Bracken** meets a carer determined to speak out.

When a rare form of dementia caused big changes in her husband's behaviour, Liz Lane faced a lack of understanding from health professionals, friends and her local community. She's now on a mission to make sure that more people know about frontotemporal dementia (FTD) and its devastating impact.

Privileged life

Liz, originally from Warwickshire, worked in management training and redundancy counselling before retiring to Cornwall in the late 1990s.

Her husband Antony, aged 80, was managing director for two international companies. They married, both for the second time, in 1998.

'We had an absolutely divine marriage,' says Liz. 'Antony was a gentle, kind and sweet person – a true English gentleman.'

They were keen sailors both at home and in the Caribbean.

'We spent most of our time on the water,' says Liz. 'It was a wonderfully privileged life.'

One of the earliest changes in Antony's behaviour came amid an unexpected family tragedy.

In 2007, not long after giving birth, Liz's daughter Amanda was diagnosed with cancer and subsequently died. Liz was travelling between Cornwall and Rome, where Amanda had lived, to help look after the baby.

'Antony was usually very caring and tactile, but I would come home late and he was fast asleep,

with no empathy or concern for our situation,' says Liz. 'It was very bizarre.'

Frontotemporal dementia (FTD)

In frontotemporal dementia (FTD), damage to areas towards the front and sides of the brain can affect behaviour, thinking, emotions and language. Although rare overall, FTD is more common among people aged under 65.

Most people with FTD are diagnosed with behavioural variant FTD, which can cause a person to lose inhibitions and be less empathetic. They also might become apathetic, or may develop repetitive, compulsive or ritualised behaviours.

In addition, there are two types of language variant FTD – progressive non-fluent aphasia causes problems with speech and grammar, while semantic dementia affects a person's vocabulary and recognition of objects.

The symptoms of these types of FTD can become more similar to each other as damage to the brain spreads. Once very advanced, they often become more like the later stages of Alzheimer's and other types of dementia.

Antony became reluctant to change his plans or routines, even when Liz wanted him to take her to hospital, and his driving worsened. He also began to drink more and behave inappropriately in social situations.

'It was a complete change in character,' says Liz. 'He was just slipping away.'

Rare condition

Liz went to her GP several times, but they wanted to hear from Antony himself, who didn't believe that anything was wrong.

'He was also intelligent enough to put up a façade, and told everyone he was fine,' says Liz.

It wasn't until he made a financial error during a business meeting that Antony acknowledged there might be a problem.

After a series of local appointments from 2009 to 2012, a neurologist declared that Antony had nothing wrong with him, even suggesting that Liz had misinterpreted or exaggerated his behaviour.

However, a medical friend told Liz that the changes in Antony's behaviour might be explained by FTD.

Within six weeks of them seeing a specialist team at University College Hospital in London, in early 2013, they confirmed that Antony had behavioural variant FTD. He was also diagnosed with Parkinsonism, where someone has symptoms similar to Parkinson's disease.

Devastated but vindicated

The diagnosis was a vindication for Liz, who received judgement, criticism and even abuse over Antony's situation from people who only associate dementia with memory or recognition problems.

She recalls, 'A fair-weather friend we used to sail with told me, "There is nothing wrong with him – you've caused this because you're so bossy and have broken his confidence."

'Another man in the village told me I'd ruined Antony's life. People said, "Watch the wife, she has serious mental issues."

'It's a double-edged sword. You're devastated that your husband has been diagnosed with a terminal illness, but

having had the finger pointed at me, it was actually a relief that I didn't have a serious problem myself. There was a huge amount of self-doubt instilled on that journey.'

Liz and Antony attended appointments at University

'Care home staff don't always understand the different approach needed for FTD, compared to Alzheimer's.'

College Hospital every six months, also taking part in research at the associated UCL Dementia Research Centre. Although visits

became too challenging for Antony, the team have continued to support them from afar.

'I'm very fortunate – they're one of the best dementia teams in the world,' says Liz. 'Anyone in the UK can be referred to them by their GP'

Antony has also chosen to donate his brain to the National Brain Appeal in order to help others with FTD.

In 2016, Antony was diagnosed with peripheral neuropathy, a form of nerve damage that affects his ability to walk. But his dementia meant he had no insight about this, which led to falls.

He moved into a care home in January 2017 and is now no longer able to leave his bed.



Lonely place

The lack of understanding about FTD that Liz has encountered across health and social care services has been glaring.

'GPs often don't know about it and smaller towns rarely have a neurologist with the knowledge,' she says.

'Care home staff don't always understand the different approach needed for FTD, compared to Alzheimer's.'

A social worker also claimed that Antony had full mental capacity, even though Liz and the neurologist knew there were many situations, involving complex decisions, where he wouldn't.

Liz has felt let down by the way some friends reacted to Antony's illness.

'There are people I had trusted who walked away when we needed them most,' she says.

'Their excuse was that they wanted to remember him as he was, but I think that's an incredibly selfish attitude.

'They don't get it and their lack of support makes your situation worse. It's a very lonely place to be.'

Everyone aware

Liz helps to facilitate a Devon and Cornwall FTD support group, part of the Rare Dementia Support service overseen by the UCL Dementia Research Centre.

'We meet every eight weeks to share personal experiences. These get-togethers are invaluable,' she says.

'FTD shatters your life – your social life is finished – so it's nice just to have a normal drink with people in a pub.'

Liz also takes comfort from the tranquillity of her Cornish cottage, which she shares with her golden retriever Polly. She lives by a creek where she can see swans and curlews from her garden.

'It's absolutely beautiful, a little piece of heaven that keeps me sane,' she says.

Devastated by the effects of Antony's dementia, Liz is determined to tackle the lack of awareness that she's experienced.

'The whole thing is so bizarre, so confusing,' she says. 'People don't know about the rarer dementias.'

'I'm going to get out there and make sure that everyone is aware.'

Next steps

- For our What is frontotemporal dementia (FTD)? (404) factsheet, go to alzheimers.org.uk/publications or call 0300 303 5933 (local rate).
- Visit alzheimers.org.uk/talkingpoint to join our online community.
- For FTD-specific support group meetings, information and advice, see www.raredementiasupport.org/ftd



Caring together

Hospice and mental health staff in Hull have been exchanging expertise to improve end of life care for people with dementia. **Gareth Bracken** reports on a collaboration that's made a real difference.

Quick read

Temporarily housed together, staff at a hospice and mental health unit in Hull have been sharing their expertise with each other.

Staff from Maister Lodge shared dementia knowledge, while the Dove House Hospice team advised on end of life care.

John Sandell, whose partner Julianna had dementia, was impressed with how staff worked together to maintain continuity of care.

Kelly Jackman, whose father Neil had dementia, says the teams provided expert and outstanding care at the end of his life.

For the past six months, Dove House Hospice in Hull has been providing temporary residence to mental health patients who have dementia.

The nearby Maister Lodge mental health inpatient unit, which treats older people including those with dementia, has been housed within the hospice while its original home undergoes a major refurbishment.

The move has given staff the opportunity to exchange ideas and support each other, take part in training and presentation days together, and even swap shifts.

Increased confidence

The new way of working has allowed the hospice team to improve their understanding of dementia.

'In palliative care a few years ago, dementia was seen as this scary thing – staff didn't feel they had the skills,' says Linda Johnson, Head of Clinical Services at Dove House.

'But it's about seeing how other people work, sharing skills and realising that it's often not that different.'

The results have been significant.

'The mental health team have given us additional knowledge, which has increased our confidence with patients,' says Dr Kirsten Saharia, a Consultant in Palliative Medicine.

Meanwhile, Maister Lodge staff have gained valuable insights into end of life care.

'We have very few end of life patients at Maister Lodge and you can be worried about whether you're doing the right thing for them, but the experience of Dove House staff put me at ease,' says Matthew Fisher, a Registered Mental Health Nurse.

'They helped with questions like, "When can you not do any more to keep someone alive?"'

Dove House staff also gave their mental health colleagues advice and support on medication, including specific guidance on using a syringe driver instead of repeated injections, which can cause distress.

'We've been back and forth supporting them with information – it's been a very enlightening time for both sides,' says Jill Monday, a sister at Dove House, who adds that the care has been very patient centred.

Sometimes, all that's required is a bit of clarification or reassurance.

'The patients are very settled in a peaceful environment on the unit, so now that we've got some really good staff relationships we can be a safety net,' says Jo Gillespie, a Senior Sister at the hospice.

Remarkable job

The joint care on offer has been praised by the families of patients.

John Sandell's partner Julianna, who had dementia with

Lewy bodies, stayed at Maister Lodge for five weeks before transferring to Dove House's hospice care, where she died aged 66.

'I didn't know what to expect, so I was relieved that it was a nice place,' says John.

'Staff from Maister Lodge were with Julie every day after she moved, to keep that continuity so she didn't feel it was all strangers.'

'I thought it was absolutely wonderful how they kept everything going like that.'

'The staff were 110% and did a remarkable job – it made me want to go and work for them.'

John's son, Julian, saw excellent examples of joined-up working during Julianna's care.

'When Mum was very angry and aggressive, the Maister Lodge staff helped with the mental health aspect while the hospice monitored the palliative care,' he says.

'Then the mental health staff backed off when they were no longer required, after checking with Dad.'

Expert care

Another patient, Neil Jackman, died at Maister Lodge earlier this year. Aged 73, he had a diagnosis of Alzheimer's but was also believed to have vascular dementia.

'The care at Maister Lodge was tailored to his needs, it was outstanding,' says his daughter Kelly.

'It didn't feel like a hospital ward – it wasn't clinical. It was just everything he required.'

Kelly and her siblings didn't want to disrupt Neil by moving him to the hospice side, so during the last 10 days of his life Dove House staff came across to support him, Kelly and the mental health team.

They took the lead on pain relief and end of life medication.

'They had that knowledge and were able to explain things step by step,' says Kelly. 'We had that expert care on hand. I couldn't thank both sides enough.'

Dying well

Both services recognise the importance of high quality end of life care for people with dementia.

'There's such a lot of focus on having a good life, but perhaps there still isn't enough focus on dying well with dementia,' says Jo Inglis, a Charge Nurse at Maister Lodge.

'Patients here have had good deaths.'

Anna Wolkowski, Chief Executive of Dove House, says the hospice is simply extending its welcome.

'Dementia is a life-limiting condition, so these are our patients,' she says.

As they prepare for the move back, the teams are making plans to continue joint training sessions and presentation days, and to set up ongoing mentoring and mutual support.

'At first we weren't even sure if we could discuss our patients with Dove House staff,' says Emma Wolverson, a Clinical Psychologist at Maister Lodge.

'On paper it seems ridiculous to bring two highly stigmatised services together, but it has made such a difference for patients and families.'



Next steps

- For our End of life care (53 1) factsheet, go to alzheimers.org.uk/factsheets or call 0300 303 5933 (local rate).
- For Alzheimer's Society training and consultancy, visit alzheimers.org.uk/training
- Dementia Action Alliance helps organisations to share best practice and take action – see dementiaaction.org.uk

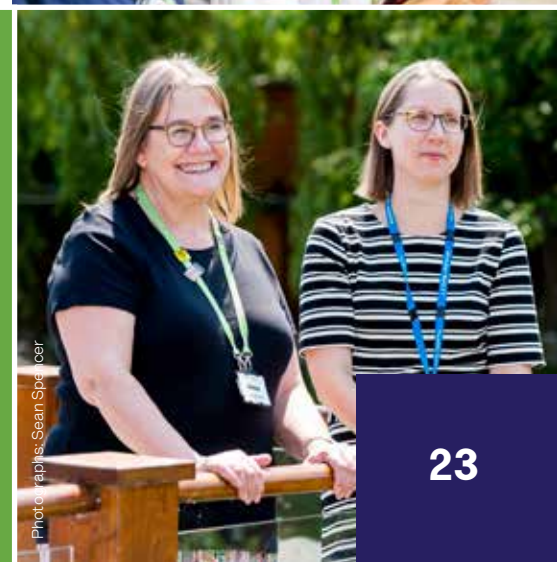


Photo: raprise, Sean Spicer

Play to win

Using creativity and imagination can boost the wellbeing of people with dementia. Gareth Bracken visits a drama group that is providing meaning and value.

At the Belgrade Theatre in Coventry, people with dementia are ready to recreate the city's greatest footballing triumph.

They are members of Living Well, a drama group tailored for people with memory problems or in the early stages of dementia.

Nine of the theatre's youth and community groups are contributing to a large-scale 'promenade' performance titled City Final, which takes the audience through stories covered by the area's iconic Coventry Evening Telegraph.

Made up of short performances and digital installations, City Final will take place across multiple floors of the newspaper's old building, just across the road from the theatre. The Living Well group have chosen to tell the story of Coventry City's famous victory in the 1987 FA Cup final. Their contributions will be recorded and played as part of the installations.

Sing together

The group sit in two lines facing each other, replicating the tunnel that links the changing rooms to the football pitch, and a microphone is placed in the middle.

In previous weeks, they have discussed and scripted the sort of thoughts that might be going through players' minds before the game, and today it's time to record.

Natalie Russo, the Drama Workshop Leader who plans and delivers the sessions, encourages everyone to think about the emotions the players might be feeling at this point, before leading the group through a final rehearsal.

An additional staff member, John Bennell, dressed for the occasion in his Coventry City shirt, is on hand to offer additional support and encouragement.

When the recording starts, each person delivers their line in order.

'We've made it!' says one.

'I hope I score a goal,' says another.

'Let's go and win the Cup!'

When everyone has spoken once, people begin to say their lines repeatedly, creating a cacophony as the atmosphere builds and builds.

Next, they record a new set of lines celebrating their team's victory.

'Bravo!'

'We won!'

'Well done, boys!'

To finish, everyone gathers closer for a rendition of Let's all sing together – a classic Coventry City song, which is rounded off with a burst of applause and cheering.

Something new

Tony Kavanagh used to go to Coventry City matches, and he attends the drama group with his wife Irene.

'I enjoy it, I think it's marvellous,' says Tony, 73, who now has dementia.

'You meet a lot of people from different parts and make friends.

'We have fun and enjoy ourselves – it puts me in a good mood and makes me want to come back the following week.'

Irene says the sessions have inspired Tony.

'He loves coming here, it's something we look forward to,' she says.

'It makes your brain work – makes you think. It's a godsend, this place.'

Mhari McLintock, now in her early 50s, was diagnosed with dementia a couple of years ago.

'The group gives me a focus for that day and something to look forward to,' she says.

'I have made new friends and taken part in activities that I have never been part of before, involving imagination and elements of play.

'I feel as though I have risked things and am willing to have a go at something new.'

Quick read

Living Well is a drama group for people with dementia run by Coventry's Belgrade Theatre.

Members have been recreating a local football triumph for use in a special performance.

Tony Kavanagh says the group puts him in a good mood and has helped him make new friends.

It has enabled Mhari McLintock to enjoy new activities involving imagination and elements of play.



Another attendee, 68-year-old Lyn Jones, doesn't have dementia but cared for both of her parents who did.

'I needed something to stimulate me, take me out of my comfort zone and make me feel better about me,' she says.

'By the end of a session, I'm on a different level. I'm happier.

'You actually see a change in other people while they're here too.'

Removing barriers

The sessions are tailored to meet the needs of everyone involved.

'We try and stay away from reminiscence, which looks purely at the past, but make it creative so that everybody can connect to the story,' says Natalie.

'We're creating something memorable that takes the emphasis off needing to remember.'

As well as their football recordings, the Living Well group has also dressed up for photographs recreating 1960s adverts from the Coventry Evening Telegraph.

Attendees with dementia are treated the same as any of the theatre's other community groups.

'Rather than putting people in a box, we don't care. In this room, everyone is equal,' says Alice Williams, Project Manager for Arts Gymnasium, the project to which the Living Well group belongs.

'We've taken measurements for a costume fitting and used professional wardrobe people. We had to adapt it, but there's always a way you can remove the barriers to provide a similar experience. It gives their participation meaning and value.

'We never want to create something that's good because they have dementia – we want it to be high quality anyway.'

Alice sees the group as a safe space for members.

'A diagnosis of dementia can be overwhelming but coming here gives people a chance to forget what is going on outside of the room,' she says.

'It's had a massive impact on people's confidence and ability to own their diagnosis.'



Photographs: Jen Mullis

Next steps

- Visit alzheimers.org.uk/dementiafriendlycommunities for more about dementia-friendly communities.
- 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/getsupport

Crocheted forget-me-nots, five hours of fun in Blackpool and some social media buzz.

Letter of the month

Beautiful brooches

I've just been reading the June/July magazine and had to write to say how much I've enjoyed it. The Q&A column really interested me, as in April this year I was diagnosed with frontotemporal dementia and can totally relate to Jules Emberton's answers.

On a brighter note, I wondered if I could share my lovely news. A dear friend Julie Cottle came to see me and brought along with her some crocheted forget-me-not brooches, which she'd been secretly making for me. She knows I did a little cake sale to raise some money, and I've recently signed up for the Memory Walk in Bristol.

I shared the beautiful brooches she made and sold 28 within an hour! She's offered to make as many as I can sell and I really wanted to thank her.

Tracey Lane, North Somerset

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

Blackpool inspiration

For the last few years Blackpool Council has hosted an annual event at the Winter Gardens, Blackpool, called Dancing with Dementia. I would like to congratulate them on this great initiative. I have attended this event twice with family members as one of them has a diagnosis of dementia and loves this event.



For an entry fee of £10, they provide five hours of entertainment – singing and dancing, organ music, ballroom and other dancing displays, a free raffle and a lunch of sandwiches and cakes.

I would truly love that something similar could be provided at other locations in the country for people in care homes or those being cared for in their own homes.

I am working on this idea in Padiham and Burnley, but wanted to encourage others to campaign for similar events elsewhere. I am certain there would be lots of local talent available who would offer their services free, and I am sure many local businesses would offer sponsorship or a free raffle prize.

Janet Dandy, Lancashire



Seen elsewhere...

On our online community, Talking Point, new member Swannykazoo asked about her uncle, who has dementia and appointed her to have power of attorney, but has since accused her of stealing. Within 45 minutes, four community members had replied to her with supportive comments and helpful advice, for which she was very grateful.

Tuesday at 9:33 AM

#8

Thanks for all this, y'all know where I'm coming from - I will persevere and try to remember that it's not personal- it's handy to have a space to unburden

A Cheshire Dementia Friends Champion was so pleased about A&E staff at Macclesfield District General Hospital, East Cheshire NHS Trust, becoming Dementia Friends that she shared a picture on Twitter.



Sian Harrison
@dementiaed

Follow

Replying to @ECTStaff @eapssn_kills and 2 others

Congratulations to the 17 A&E staff who are now Dementia Friends



Many people were so pleased to see Argos's news that the high street retailer is supporting us in its latest charity partnership that they responded on Facebook.



Martin Abbey Well done Argos. Anything that helps tackle this cruel disease is welcome

Like · Reply · 4d



Will to remember

As peak wedding season draws to a close, it's important to remember that a previous will is no longer valid after you marry. Will to Remember is the perfect solution for anyone making or updating their will – select a participating solicitor in your area and get £150 off the cost while supporting Alzheimer's Society. Find out more at alzheimers.org.uk/wills or call 0330 333 0804 (local rate).

Helpline recognition

Our National Dementia Helpline has been praised by Helplines Partnership, who reviewed the support we offer over telephone, email, Live Advice Online and social media.

In renewing our accreditation with them, they were particularly impressed by the excellent tone, pace, empathy and building of rapport during calls.

Our helpline is here for anyone who needs information, support or advice about dementia.

'Some of the calls are more straightforward, while some clients require detailed information or emotional support. We support everyone, no matter what their situation,' said Cynthia, a Helpline Adviser. 'We put quality over quantity and concentrate on the caller's needs – we put them first.'

You can contact our National Dementia Helpline on 0300 222 1122 (local rate).



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 October/November issue to arrive by 7 September. Views expressed are not necessarily those of Alzheimer's Society. Letters may be edited.

**John Holt**

Preston, aged 69 with vascular dementia

What's changed most since your diagnosis?

I don't have the same life as before but make the best of it. If it was just the dementia, I would still be able to go to the gym and swim, but not with my other conditions (spinal stenosis, angina, Crohn's disease and macular degeneration). I keep my independence as much as I can.

What would you take to your desert island?

I've always liked Johnny Cash, and I'm learning 'Hurt' for Singing for the Brain. He had a tough life. Because you know what he's gone through, you know what he's singing about. You can't copy something like that – you've got to do it in your own way.

How has Alzheimer's Society helped you?

I enjoy the Focus on Dementia Network, which has led to other things. I was interviewed at a local charity for people who are visually impaired – blind people can also have dementia. Doing things for Alzheimer's Society has given me confidence. It keeps me thinking.

What is your most treasured possession?

I don't own them, but my family and friends. I don't think I could do without them. My wife supports me and helps me through things. Everybody gets dark days and your family gets you out of that. I was in London with my 12-year old grandson and I was struggling with walking. He said, 'Don't worry, I'm not going to leave you.'

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.

My daughter has had a baby, so we phone Ma to tell her the news. She sounds delighted: 'Ooh! Not many of us get to be great-grannies do we?'

Do we know the name? We tell her. 'Hmm, he'll be known as Freddie. But don't tell them I don't like the name.'

We remind Ma that they revealed the baby's name on our last visit and she made it clear that she was very much against it then. Asked for an alternative, she had suggested Brian. Yet later that day, when my daughter asked about calling the baby Brian, Ma was equally adamant that this was a terrible name.

Ma continues to live as well as she can with dementia. Aside from her forgetfulness and inability to cope with much on her own, she maintains many long remembered skills. She washes and dresses herself in her usual stylish clothes, and reads 'instructions for the day' on the big whiteboard in the kitchen.

She's a late riser, and she's rarely up before noon. The high temperatures don't seem to bother her, as she's always been a fan of sunshine.

We really appreciate Ma's 'fighting spirit'. She was always one to make pronouncements on whatever she felt was right or wrong, and she is still capable of glaring at us and telling us off, however strange we might find her reasoning to be!

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

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A group of people with dementia in Cambridgeshire try out products designed to help keep track of appointments and tasks.

Reminders

We visited Open Minds in Peterborough on a sunny July afternoon to see what they thought of a range of reminder products.

This warm and chatty group of people with dementia catches up weekly at the cathedral city's Dementia Resource Centre. As the bees buzzed among the lavender out in the specially designed garden, group members were busy exchanging jokes and news.

We had brought four products with us, all available from our online shop, that help people to keep track of appointments and tasks. Two were reminder clocks, while the others use dry-wipe surfaces that you can write on and reuse.

Reminder clocks

We showed the group two electronic clocks – the Rosebud and MemRabel 2 – that display the time and date in a choice of formats, and which you can program with reminders. They can

stand on a table top or be wall mounted, and both have a range of built-in reminders that use different combinations of audio, video and images.

Barry and John both found it fairly straightforward to set up reminders on the Rosebud using the buttons on its back.

'I'd have that in my bedroom,' said Barry, 'I'd use it for appointments.'

Everyone enjoyed the fact that the 'It's time for tea' reminder, which John had programmed into the Rosebud, went off just as a round of cuppas arrived.

The MemRabel 2 has a greater number of options when setting reminders, and also has a remote control. Ellie got the hang of programming it in this way, though Joan and Colin found it difficult to find the right pressure for the remote's small buttons or to hold them down for the required time.

You can add your own recordings and images to use as reminders on both clocks by transferring

them from your phone, computer or camera using a USB stick or SD memory card. Barry thought it would be easier if you could record them straight into the devices themselves, and if you could type in written reminders.

Maureen thought many people would rely on someone else's help in setting up reminders, and this might be a problem for a person who doesn't have this kind of support. They also both need to be plugged in to the mains to work.

Neville liked the visual reminders, but wasn't keen on the voice used in the Rosebud audio reminders and so would want to record his own. The voice in the MemRabel 2 reminders was too soft for some to make out among the hubbub of the room.

However, people liked the chimes that could be set to come on before reminders on both clocks – these catch your attention so you know to listen or look out for the message.





Dry-wipe reminders

Open Minds tried out two products with dry-wipe surfaces, which can be written on using whiteboard markers and then erased and used again.

The Dry-wipe reminder frame is an A5 whiteboard that comes with a stand and marker pen. It has 'Things to do today' printed across the top, with space for six items beneath.

Colin thought the frame was a good idea, and asked whether the 'today' was permanent, as he might want to add reminders for a later date. Although it can't be changed, Jon said his mum uses the frame and just ignores the word 'today' if it's not relevant.

The Dry erase sheets are a Magic Whiteboard product – these are thin sheets of plastic that cling to most surfaces without actually sticking to them, so can be reused for different notes in different places and times. They come in a pack of 20 A4 sheets.

Norma thought the sheets would be useful for leaving herself reminders on the backs of doors around the house. Doug was also enthusiastic about them, especially as prompts to take medication.

For these and other reminder products – as well as many other useful aids and gifts – see shop.alzheimers.org.uk or call 0300 124 0900 (local rate).

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

The reminder clocks are exempt from VAT if bought for a person with dementia or other condition – if so, then the Rosebud reminder clock, which also comes in a black frame, is £69.99, while the MemRabel 2 is £95.83. The Dry wipe reminder frame costs £12 and a pack of Dry erase sheets is £10.



See p39 for a chance to win a Rosebud reminder clock or dry-wipe reminder frame.

Photographs: Derek Coard

'My neighbour has dementia and lives alone. She's lost weight and isn't changing her clothes or going out. She says all is fine, but I'm worried – what can I do?'

Safeguarding concerns

It's hard to know what to do if you're concerned about someone's wellbeing, yet they tell you everything is fine. This could be the case whether or not they have dementia, though you might have particular worries if they do.

If your neighbour has any family or friends who visit her, perhaps find out if they know what is happening and whether they could help. If this isn't possible, you can share your concerns with local social services.

Self-neglect

Self-neglect – where a person isn't looking after themselves as well as they should be – can get worse and lead to many problems.

If you raise a safeguarding concern about your neighbour with social services, they have the power to look into it and work out how best to help her. They could find out what she needs to stay healthy and well at home.

Going to social services might seem like an extreme thing to do. However, if your neighbour is telling you that everything is fine and you feel that it really isn't, then it's important she gets the support she needs. Contacting social services – who can find the right solutions with her involvement – could be a vital step in helping her.

Other concerns

As well as self-neglect, there are a number of other signs of possible abuse or neglect that could be a reason to raise a safeguarding concern with social services.

- **Noticing signs of financial abuse – for example, the person lacks money for basics like heating or for other things they'd usually spend it on, they're befriended by someone new who may be taking advantage of them, or they're repeatedly buying items from sales callers.**
- **Spotting bruising, cuts, burns or other marks on the person.**
- **Witnessing or hearing arguments that appear more severe than you'd expect, for example they may include verbal or physical abuse.**
- **Not seeing someone for a long time – especially if you'd usually expect to see them, or if they miss something they regularly go to. You might notice their bins not being put out or post not being picked up.**

If you believe that someone is in any immediate danger, then you should call 999 – that is what the emergency services are there for. In other cases, a call to social services could lead to them finding out what can be done to help.

For further information or advice from Action on Elder Abuse, visit www.elderabuse.org.uk or call 080 8808 8141.



Photograph: iStock.com/PeopleImages



Fear of being judged may prevent you sharing how you're feeling, but our online community is full of people who understand.

Moving decisions

Agreeing that a person with dementia needs to move into a care home is something that many people describe as the most difficult decision they've ever had to make. This is especially common when the person is your partner, but it can be just as true in other situations too.

Even when all the facts are telling you that it's the right thing to do, it's normal for this to be a highly emotional time. You might have feelings of guilt or of letting the person down in some way. When you've been sharing your life or a home with them, you may also feel a sense of loss.

Fearing other people's judgement could discourage you from talking about your feelings. People often end up feeling that they have to cope with everything on their own.

No judgement

Sharing what's happening and how you feel on Talking Point, our online community, can help you come to terms with this decision, secure in the knowledge that no one will judge you.

Many community members will be going through similar situations, or will have in the past. Knowing that they understand what you're dealing with can be comforting in itself.

They may offer practical suggestions before, during and after the move, as well as simply being there for you through a difficult time.

Safe and supportive

Talking Point provides a safe and supportive place where you can share how you're feeling and find out how other people have managed. If you sign up as a member and want to discuss something more private, you can also take part in the 'dealing with difficult feelings' forum. Here, your posts can only be seen by other Talking Point members.

Being able to share experiences, advice and feelings with people who have a good idea about what you're facing won't make all your problems disappear. However, it can make a massive difference by helping you to feel less alone and better able to cope.

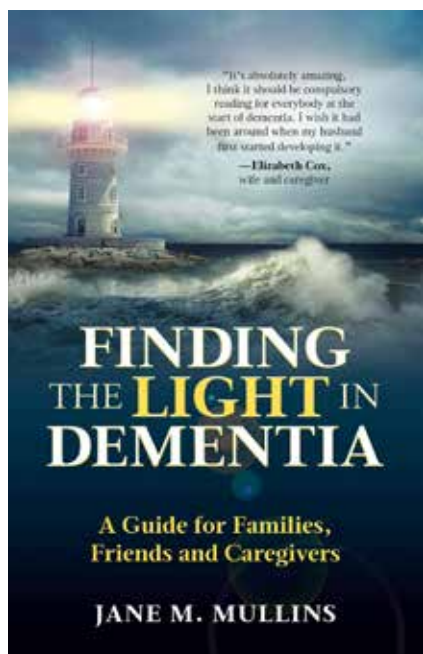


Join in

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

Readers tell us what they thought of this book for family, friends and carers of people with dementia.

Finding the light



As a dementia nurse consultant with many years' experience, Jane Mullins has a lot to share about good care. This book is her attempt to share it in a way that is helpful to anyone supporting a partner, relative or friend who has dementia.

Caroline Branney, who manages our Dementia Knowledge Centre, warns against making the proverbial mistake about judging books.

'Initially slightly put off by the cover,' says Caroline, 'I was converted by its practicality, sensitivity and relevance.'

Marilyn Shipp, in Kent, was wary of drawing conclusions too soon about a book that gave her so much to think about. 'There are so many sensible and helpful

pieces of advice and ideas, it all needs time to digest and take on board!'

Despite this, she adds, 'The book is well researched and seems to cover all the things you need to know to be able to care for your loved one with dementia, as well as it is possible to do so.'

'It gives insight into their feelings, and helps you to find ways to cope with the many difficult situations that continually arise. I also find the summary at the end of each chapter very useful.'

Range of readers

Caroline says the book would be helpful for a range of carers.

'The book is written mainly for the person caring for or sharing their life with a person living with dementia, from diagnosis to considering a care home,' she says.

'Throughout, the author uses "you and your partner" to address the reader, which works well, and by mentioning issues such as working, driving and children, it feels appropriate for a wider age group of carers.'

Janet Dandy, in Lancashire, goes further, 'I would say it is an ideal and very comprehensive book for anyone with a friend or family member newly diagnosed, or who has not previously had any training or written information about dementia. It would also be useful for professional support workers.'

Useful content

Caroline likes the way the book is structured. 'The use of bullet points at the end of each chapter and the space for notes means a carer could jot down thoughts and consult it regularly.'

'There are quotes from people with dementia and others, which provide relevancy and break up the chapters. I found it easy to read and absorb.'

Janet agrees, 'It is very easy to read, with lots of advice about everyday practicalities such as eating, washing, dressing and safety. Additionally, the author describes ways to keep the person stimulated and still able to enjoy life via music, art, memory books and boxes, and nature.'

'It concludes by discussing the possibility of the person needing admission to a care home and advises how to face this and choose the best home.'

'The sequence of subjects covered is appropriate,' says Caroline. 'For instance, Chapter 7 on eating and drinking starts with diet, signage in the kitchen and eating, and follows with the importance of dentistry and good physical health.'

'Chapter 11, Caring for the caregiver, stresses not ignoring the emotional, physical and social upheaval that you are experiencing. The tips about not coping alone and for looking after yourself are clearly described and valuable.'

'I also particularly liked the chapter 'I am still me!' about maintaining the person with dementia's dignity and individuality.'

Compassion

Janet feels the book was written with compassion for both the person with dementia and those supporting them.

She adds, 'It would give a sense of hope and optimism by describing how some creative thinking and changing our reactions to a different response can make a huge difference to the carer and cared-for.'

Marilyn expects to enjoy 'continually referring back to the suggestions and ideas'.

Finding the light in dementia: A guide for families, friends and caregivers, by Jane M Mullins (DUETcare, 2017), 226 pages, £12.99, ISBN: 978 1999926809.



Your turn

For the next issue, we invite you to read **The memory activity book**, by Helen Lambert (DK, 2018), 224 pages, £16.99, ISBN: 9780241301982.

Let us know what you think about this book by 10 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 15 August quoting 'Activity' for a chance to win one (see p39 for terms and conditions).

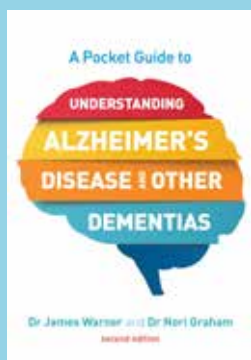
Other useful resources



Audio library

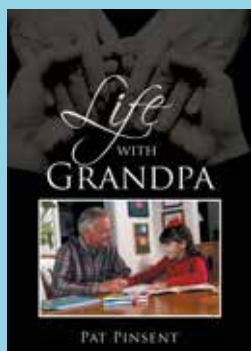
Calibre Audio Library is a charity providing unabridged audio books for people who have difficulties reading print. A huge range of professionally recorded fiction and non-fiction titles are available as MP3 files on CD or memory stick, or to play online. A one-off £35 fee allows unlimited access, and you can sign up for a three-month free trial initially.

See www.calibre.org.uk or call 0 1296 432339 for more information.



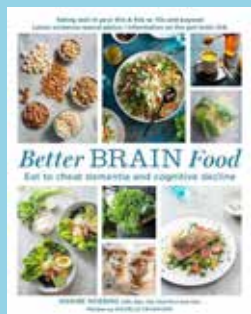
Pocket guide

Written by leading experts, this recently updated book helps people to better understand Alzheimer's and other dementias. It provides clear and concise information on symptoms, diagnosis and treatments, getting help and support, tips for people with dementia and advice for carers. It's also one of the Reading Well Books on Prescription for dementia (see www.reading-well.org.uk/books). **A pocket guide to understanding Alzheimer's disease and other dementias**, by James Warner and Nori Graham (Jessica Kingsley, 2018), 160 pages, £9.99, ISBN: 978 1785924583.



Life with Grandpa

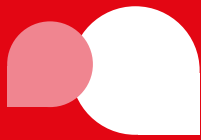
This story, written from a young girl's point of view, provides insight about how a child might experience an older relative's dementia. Its easy style suits a range of ages, including older children and teenagers. **Life with Grandpa**, by Pat Pinsent (Author House UK, 2018), 76 pages, £8.95, ISBN: 9781546285809.



Better brain food

An international expert on nutrition for older people presents a compelling argument that the food you eat can make a big difference to your quality of life as you age. The book includes over 70 inspiring recipes with photographs. **Better brain food**, by Ngaire Hobbins and Michelle Crawford (Murdoch, 2017), 240 pages, £17.99, ISBN: 978 1760527549.

We have three copies of **Better brain food** to give away – email magazine@alzheimers.org.uk or write to the address on p3 by 10 September quoting 'Food' for a chance to win one (see p39 for terms and conditions).



Talking Point members share tips about getting the right continence products for a person with dementia.

Continence products

'If you want free pads you need a referral to the continence service, usually via your GP. Then it's down to their budget how many they are going to give you. Nappy-style pads are cheaper than pull-up pants. We got pull-ups but had to buy loads in ourselves, as we weren't given enough. You can buy them online but you can also get them in supermarkets and pharmacies (supermarkets sell them cheaper than pharmacies).' **Beate**

'Incontinence pads are free in Northern Ireland. The GP will refer you to the continence service and you will see a nurse. My mother started off with mini pads then pads then gradually increasing strengths of pull up panties. They will only allow two pairs of panties per day. There is a review once a year by a nurse but this can be done by phone. You get a number to ring for more pads. You can ring the nurse if you need stronger pads.' **angelaraphael**

'We sometimes wrap an extra, but smaller, incontinence sheet inside Mum's nightie, for overnight. This saves a wet nightie (or sheets) when there's a leak. I've found the urine incontinence one of the hardest things to manage with Mum's dementia, especially now she's practically bed bound.' **Marnie63**

'My other half has major problems with kidneys and bladder, pees constantly. We do get supplies via the incontinence nurse, pads and the overnight nappy type. I can cope with changing the pads throughout the day, I have to do them as he just can't get his head round how he should do it.

'The overnight one is for very severe incontinence but he passes so much overnight I put a Boots night-time pants on top. It is very rare for his night things and the bed covers not to be wet in patches, especially if he lies on his side. Trial and error – I can now keep the bed dry by covering it in a washable double-bed sheet cover and using two disposable bed covers on top of that. I wake up numerous times feeling him and the bed, checking for wetness.' **Sad Staffs**

'The only problems we had were when we put Mum in the wrong size. Then we had leaks. Now we know which ones to get it has made a huge difference. Mum is doubly incontinent too. The only thing I find is, unless I tear the sides to get them off, then it can be messy when pulling them down as Mum doesn't stand still for long. It works for us that way though.' **Bluelilly**

'I use Tena pants for my mother, who is doubly incontinent (not all the time, but often enough). She has had these since being in hospital and they have only leaked a tiny amount on one occasion. The hospital sent her home with the net pants with separate pad and a spare, but she really didn't like them. I found they were quite difficult to get up on my own, especially as Mum couldn't stand for too long – we needed a quick pull-up job and she feels as if she is still wearing "normal pants".' **degu68**

'Less volume but more frequency is a bit of a trade-off but it might work. It's worth thinking about because then you might be able to use a lighter pad – you'd have to change it more often but you'd save on washing sheets.' **KevinL**

'Boots do a good delivery service, where a plain box turns up with a bulk order – easier than carting them home or gambling that your local branch has enough supplies.' **Helly68**

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



Next issue

Do you have any advice about what to do when a person with dementia doesn't want to attend regular check-ups, for example with the dentist or optician?

Email magazine@alzheimers.org.uk or write to the address on p3.



Films and cinema

Watching films, at home or at the cinema, can be rewarding and entertaining, and often prompts conversation. Many people with dementia continue to enjoy seeing new films, as well as the ones that remind them of earlier times.

Simply watching older films may encourage reminiscence, as can film-related activities. One idea is to match printed pictures of famous scenes with printed quotes. You could ask people what film they'd take to their 'desert island', and use YouTube or Google to find online clips.

In addition to watching old and new films on TV, there's something special about going to the cinema. Dementia-friendly screenings are held by many multiplexes as well as smaller, independent cinemas. These may keep lights raised slightly throughout the film and include intervals, and have a relaxed feel where it's OK for people to talk.

We want all cinemas to be dementia friendly all of the time – if you think your cinema could benefit from our guidance, point them to alzheimers.org.uk/cinema

The CEA card is a UK-wide scheme where carers can get into most cinemas for free if they are supporting a person with dementia – see www.ceacard.co.uk or call 01244 526016.

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).

When does the NHS pay for care?

This booklet is for people who need long-term support from the NHS or social services because of dementia.

It explains:

- what NHS continuing healthcare is
- how assessments are carried out
- what to do if it is not awarded.

Call **0300 303 5933** for your free copy or email orders@alzheimers.org.uk quoting code 813.





Keep up to date

Care and cure is the research magazine of Alzheimer's Society. To receive a copy of this magazine quarterly, please sign up at alzheimers.org.uk/careandcure

Take part in research

Sign up online at www.joindementiaresearch.nihr.ac.uk
Call 0300 222 1 122 and ask about Join Dementia Research.

Join our Research Network

Involving people with dementia, carers and former carers to influence our research.
alzheimers.org.uk/researchnetwork

General enquiries

enquiries@alzheimers.org.uk

Aoife Kiely

Research Communications Officer
aofe.kiely@alzheimers.org.uk
020 7423 3522





Reminders competition

We have a Rosebud reminder clock for one lucky winner and Dry-wipe reminder frames for two runners-up, drawn from correct entries received by 7 September.

Q: The classic film that revolves around the meaning of a media mogul's final utterance, 'Rosebud', is:

- A. Citizen Smith.**
- B. Citizen Camembert.**
- C. Citizen Kane.**



Christmas card competition

We have a pack of 10 of our exclusive winning Christmas card design for each of five winners drawn from correct entries received by 7 September.

Q: The line that first follows 'While shepherds watched their flocks by night' in the popular carol is:

- A. Small creatures gathered 'round.**
- B. All seated on the ground.**
- C. Five gold rings.**

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

Womenswear competition

D McKillen in County Antrim won a pink 'Camilla' shirt, R Hallowell in Oxfordshire won a ginkgo print 'Linda' wrap skirt, and M Butler in Greater London won blue 'Anna' socks. Answer: In the long-running TV series The Muppet Show and its associated films, the chicken who is also Gonzo's love interest is called Camilla.

Book giveaway

The five readers who each won a copy of Finding the light in dementia, by Jane M Mullins, were K Sneddon in Renfrewshire, H Carter and J Dandy in Lancashire, M Shipp in Kent and M Langham in North Yorkshire.



Who will you walk for?

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

Sign up at
memorywalk.org.uk

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

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