WALK FOR MY WIFE
For her courage in her confusion
For a world without dementia

Sign up now at memorywalk.org.uk
or call 0300 330 5452 to find out more.
Welcome

As a new addition to the Living with dementia team, I’d like to take this opportunity to introduce myself. I’ll be working alongside the editor, Danny Ratnaike, to produce regular articles for the magazine and I am really looking forward to telling the honest and inspiring stories of people affected by dementia.

I’ve already had the pleasure of attending Worthing Town Cryers, a service user review panel in Sussex. It was fantastic to see a group of people so motivated in addressing local and wider-reaching issues. It was also an excellent example of the ways in which the Society involves and listens to people with dementia.

Long may that continue – we will certainly try to reflect the same spirit within these pages.

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News

Get baking for Cupcake Day: 16 June

The Society’s first Cupcake Day is being held on 16 June and we are asking our supporters to bake, buy or eat cupcakes together to raise funds.

Anna Riley, Senior Marketing Executive, said, ‘We’re calling on all cake lovers from Penrith to Penzance – and everywhere in between – to get involved and join our cupcake crusade.

‘Whether you want to hold a cupcake sale or simply indulge in a tasty treat, everything you do to support Cupcake Day on 16 June will help Alzheimer’s Society raise the vital funds we need to defeat dementia.’

Cupcake Day has been launched in association with woman&home magazine and is being advertised through a bright, bold campaign. With the involvement of our celebrity supporters and others, we hope to raise £500,000 from the day.

You can host a Cupcake Day event at home, at school or in your place of work, recruiting friends, family and colleagues to bake, eat and donate.

Visit cupcakeday.org.uk to request a cupcake kit, which includes everything needed to create the perfect cupcake event.

Neglected topics

The national Dementia Action Alliance discussed issues that can often remain unspoken at its recent quarterly meeting. A range of speakers spoke to 65 delegates about lesbian, gay, bisexual, and transgender (LGBT) issues, intimacy and cultural perspectives.

Sarah Tilsed, Dementia Action Alliance Engagement Officer, said, ‘We thought these topics would create discussion and make members start to think outside the box.

‘We hope delegates told colleagues and friends what they learned and took some action, for example looking at whether their services consider the needs of LGBT and black, Asian and minority ethnic communities.’

Future discussion topics include the devolution of health and social care, and legal rights such as what happens to someone who allegedly committed a crime prior to getting a diagnosis and is now going to trial.

For more about the Dementia Action Alliance, see www.dementiaaction.org.uk
Dementia Awareness Week: A big thank you

Thank you to all of our supporters who took part in this year’s Dementia Awareness Week, which saw around 700 events take place from 15–21 May.

Events included a pop-up shop in Leicester’s Highcross shopping centre and a roving photo booth in Bradford, where people had their picture taken alongside what they would say to dementia.

A City Lights Supper at Belfast’s City Hall (pictured lit up in the Society’s colours) was attended by the Lord Mayor, while actor Richard Hawley joined a Singing for the Brain group in London. In Cardiff, there was also a film screening about a woman’s journey with dementia.

The hashtag #DAW2016 trended no.1 on Twitter as people shared their messages to dementia. One Twitter user, Lydia C, wrote, ‘My mum’s memories may be fading but our love will not! One day you will be beaten!‘

The week also included the third ever busiest day of people visiting the Society’s website for information and support.

Not just dementia

A new report is calling for better care for people who have dementia alongside other conditions. The All-Party Parliamentary Group (APPG) on Dementia says the current system is too fragmented and that care in such cases is ‘substandard’.

Seven in 10 people with dementia live with at least one other long-term condition, and this can cause problems such as forgetting whether they have taken medications for these.

One of the APPG’s recommendations is for people with dementia to have an annual health review co-ordinated by their GP that looks at all of their conditions together.

George McNamara, the Society’s Head of Policy, said, ‘The system is persistently failing people by not providing them with someone who has the proper oversight of their health and wellbeing to co-ordinate their care.’

For the full report visit alzheimers.org.uk/appg

People Awards 2016

Congratulations to all winners and nominees in this year’s People Awards, which recognise the work of Society volunteers and employees. Categories included Outstanding Contribution, won by Hilary Doxford, a Research Network volunteer who has Alzheimer’s and who has ‘worked with others to create platforms that build the voice and influence of people affected by dementia’.

Quick read

This is the June/July edition of Living with dementia, the magazine of Alzheimer’s Society.

A man with vascular dementia in Merseyside talks about overcoming his anxieties about attending local groups.

We hear from a carer in London who is taking part in research to find out more about how dementia may be prevented.

The Herbert Protocol in South Yorkshire is making searches for missing vulnerable people quicker, easier and less distressing.

Living Words is enabling people with dementia to be heard and understood, even when communication becomes difficult.

The magazine also includes dementia news, updates on our work and opportunities to get involved and share your experiences.
In the press

Promise but no cure

Recent research findings led the Daily Express to declare ‘Alzheimer’s cure at last’ on its front page.

Unfortunately there is not enough evidence yet to say that the drug concerned will definitely benefit people with dementia, much less to declare it a cure.

A drug used to treat type-2 diabetes, called liraglutide, has shown promise for the treatment of Alzheimer’s disease.

Researchers in Denmark recently published results of a 26-week test of the drug on 38 people. The drug did have some effects on the brain, but the trial was not large enough to show if it had any benefit on memory and thinking.

The Society is funding research to find out whether liraglutide could help people with Alzheimer’s. This trial is recruiting participants with early-stage Alzheimer’s disease (MMSE score of 22 or higher) in London, Southend, Brighton, Southampton, Bristol, Northampton, Wolverhampton, Birmingham and Cambridge. More recruitment sites will soon be opening across the country.

To find out more about participating in this trial, email memory@imperial.ac.uk or call 020 8383 3704.

£250 million for research institute

A quarter of a billion pounds has been pledged to create the UK’s first Dementia Research Institute – £50 million each from Alzheimer’s Society and Alzheimer’s Research UK, and the rest from the government.

The institute will enable research into care, prevention and how technology can be harnessed to tackle dementia as well as biomedical research. Set to be up and running by 2020, it will have a central UK hub with a network of regional centres.

Doug Brown, Director of Research and Development at the Society, said, ‘Our involvement will ensure that the priorities of people affected by dementia are addressed in the research taking place at the institute.’

‘We will also bridge the gap between research, policy and care to ensure research findings are rapidly translated into improvements for people living with dementia and their families.’

See alzheimers.org.uk/research for more about our research programme.

End GP care home charges

Alzheimer’s Society has found that one in five GPs in England are charging care homes for services that should be free. Our latest Fix Dementia Care report also says that people with dementia in care homes struggle to access vital care from physiotherapists, continence services and dentists.

The report was released as part of our Fix Dementia Care campaign, which launched in January with a focus on standards of hospital care.

We are encouraging supporters to sign a petition demanding that health secretary Jeremy Hunt puts an end to GPs charging to provide care to people with dementia in care homes.

Sign the petition at alzheimers.org.uk/endGPcharging

Your caring stories

Carers are being asked to share their experiences in a new survey to help shape government strategy.

A Department of Health consultation – How can we improve support for carers? – is seeking responses from current and former unpaid carers in England as well as people who have someone care for them.

‘Caring for someone with dementia is different to caring for someone with a different condition, so it is important that this unique perspective is heard and considered,’ said Martina Kane, Senior Policy Officer at the Society.

‘We want dementia carers to have their say, as the strategy will set the path for how services will look over the next five years.’

For more information and to take part in the survey, visit www.tinyurl.com/jp5kumk
Volunteers on board

Two Society volunteers will join our Board of Trustees this year. Active volunteers are being recruited to strengthen the board’s understanding of the needs of people affected by dementia and the work of our volunteers.

Chris Powell, a Trustee since 2012, said, ‘We need volunteers as fellow members of the board to keep our work well grounded in the experience of those who are daily in the front line.’

If more than two candidates are shortlisted, then registered volunteers, Dementia Friends Champions and former Society members who have opted in will be able to vote for the new board members in July and August. Those eligible would receive a pack by email or post in July.

In briefs

Dementia Friendly Awards

Nominations for this year’s Dementia Friendly Awards, celebrating individuals and organisations who are leading the way in creating dementia-friendly communities, are being sought until the end of June. To nominate, visit alzheimers.org.uk/dementiafriendlyawards

Daily living aids

Look out for our new daily living aids catalogue, featuring a great range of products to help everyday life for people affected by dementia. See alzheimers.org.uk/shop

Virtual Advisory Board

Another new way in which we are involving more people in what we do is our Virtual Advisory Board – see the ad on p27.

Summer events

The Society will be reaching a range of communities through more than 30 events this summer, as diverse as air shows, agricultural shows and lesbian, gay, bisexual and transgender Pride festivals.

Key events include Pride in London, where our supporters will join the parade through the city centre, as well as the Clacton Air Show (pictured) and Royal Welsh Show – the biggest agricultural event in Europe.

Michael Richardson, Conference and Events Officer, said, ‘Our summer events allow us to continue to engage our core audience, albeit in a different setting, while also reaching other communities that may not seek out our traditional roadshows.’

New Chair

Alzheimer’s Society welcomes Stephen Hill as the new Chair of our Board of Trustees. An experienced business executive, Stephen will take up office at our AGM in September.

Memory Walk 2016

Join thousands of others this autumn to walk for a world without dementia in our biggest Memory Walk yet, with 31 flagship walks around England, Wales and Northern Ireland. Sign up to Memory Walk 2016 at memorywalk.org.uk
Next steps

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

- Visit alzheimers.org.uk/publications for our factsheets and other resources, or call 0300 303 5933 (local rate).

- For ways to support the Society, go to alzheimers.org.uk/getinvolved or call 0330 333 0804 (local rate).
Opening the door

When John Kelly first went to a group for people with memory problems, he wasn’t sure he’d be able to cross the threshold. Luke Bishop hears how he now helps others overcome their anxieties.

When John Kelly was persuaded to attend a group for people with memory problems in St Helens, Merseyside six years ago, he was so nervous that he sat in his car for 10 minutes before going in. Even after plucking up the courage to enter the building, he had to stop again before opening the door of the meeting room.

John, now 65, had been diagnosed with vascular dementia the previous year after a number of instances of forgetfulness. These had affected his work as an electrical and plumbing engineer in particular.

After diagnosis he took early retirement and, out of work for the first time in his adult life, says he entered a ‘dark place’ for several months. He barely left his house or spoke to anyone, worried that people would be talking about his condition and judging him for it.

All this was playing on John’s mind when he went to attend the group, and it was touch and go as to whether he would be able to overcome his anxieties.

Fear and embarrassment

When the group was first suggested, John dismissed the idea immediately, thinking it was simply not his sort of thing.

He says, ‘At this stage I hadn’t really been out for about six or seven months for fear of people recognising what condition I had.

The group is not about me making decisions for everyone else on what we should do. Whatever is the decision of the majority of the people, that is what is going to happen.

It was an embarrassment to me and that is how I saw it.

‘The psychiatric nurse told me about this meeting and I said I would think about it, but had no intention of going. Vivian, my wife, then chatted to me about it and said, “You can let it take over you, or you can fight back and get your life back.”’

As Vivian had foreseen, attending the meeting was to be a life-changing experience for John and something that initiated his ‘fight back’ against dementia. He recalls, ‘When I went in I could have died – there were quite a lot of people around a big table talking, but talking really quickly – and it frightened me. I had a fear of everyone talking to me really quickly and not being able to cope.

‘However, a lady there said to me, “Sit down John,” and eventually I started to come to terms with the situation – I wasn’t happy but was coming to terms with the fact I was there.’

Playing his part

Going to the group the second time was a lot easier for John, and he felt more able to talk about his experiences of living with dementia. When people were asked if they would like to establish a regular group, John was very keen to play his part.

‘That was the moment that I founded the Looking Forward Dementia Support Group, for which I am now chairman, along with Tish McKee, who works with people with dementia and their carers.’

From that point on the new group started to meet on a monthly basis. It describes itself as an innovative and forward-thinking group that aims to inform, expand, educate and enhance knowledge and understanding of what it is like to live with dementia.

The group grew organically and, at first, the main aim was to gauge the level of interest and
engagement that there would be for it in St Helens. They quickly discovered a significant amount of interest.

**Friendship and support**

John says the group became a great source of camaraderie, friendship and support for those who attended, and not least for himself.

Many new members seemed to have gone through a similar experience to him, doubting the benefits of joining a group and uncertain about wanting to be there or engaging with others. In most cases, however, such reservations were soon overcome.

‘With me being the chairman as well, I saw all the people coming through the doors. At first, they often look frightened and confused and like they are thinking, “What the heck am I doing here?” – just like I was at my first group meeting.

‘You can see the worry on their faces. But my motto now is that if that person doesn’t leave the meeting with a smile on their face or talking to other people, then I haven’t done my job properly. The majority of time they accept the situation that they are in and learn that they are in the right place.

‘We offer people peace of mind. The way forward is not to let dementia ruin you but to stand up and rule the dementia. In the group we take the mickey out of it and the effect it has on us. We say things like, “If I knew dementia was going to be this good when I am trying to fight it then I wish I would have had it earlier.”

‘When someone is feeling sorry for themselves that is another time when people rally around to make the person feel better. You chat to people and you get them involved.’

**Out and about**

Although the focus has mostly been on providing companionship and emotional support for people with dementia, John says that going on trips is increasingly becoming part of the group’s remit.

A recent excursion to a museum in Yorkshire was very well received, and he is planning a series of nature walks so that members can take part in activities such as bird-watching. The group also acts as a source of information, with talks from Alzheimer’s Society and other organisations.

John says, ‘The group is not about me making decisions for everyone else on what we should do. Whatever is the decision of the majority of the people, that is what is going to happen.’

Speaking more generally about overcoming barriers to attend groups he adds, ‘Once you go over that threshold, that is the first step and that is the major step. You may not have been out of that front door for months or years but as soon as you make that first step, that is the road to creating a better way of living with dementia.’

**A better life**

Although John went through a tough time after diagnosis, his current mission to try and make life better for other people living with dementia is influenced by the grit and determination he has shown throughout his life.

For example, he attended night school as an adult so that he could fulfil his ambition of becoming a union shop steward by learning to read and write. This later led to him becoming a full-time union convenor.

The other mainstay in his life has been Vivian, whom he credits with helping him get out of his initial period of depression after diagnosis. She insisted that he should do what he can to live well with dementia rather than letting it stop him in his tracks.

These positive influences have helped him form his overall philosophy on life with dementia.

‘You can take dementia two ways – and this is just my way of looking at it – it is like a motorway and you can stay in the fast lane and get to your destination quickly, or you can go on the slow lane and learn how to cope with it and get a better way of life out of it.’
John Kelly was diagnosed with vascular dementia in 2009. For months after this he barely left the house because he felt embarrassed about his condition and its effects.

A year later, John was persuaded by his wife Vivian and a psychiatric nurse to try a group for people with memory difficulties in St Helens.

Despite his worries, he went along and even helped set up a new group, the Looking Forward Dementia Support Group.

John sees many other nervous and unsure people coming to the group, but says that if they aren’t happy by the time they leave then he has not done his job.

He believes that being part of a group can be positive for people with dementia, and that it is important to take the first step.
Society

Having a real say

More people with dementia are influencing a range of local and national work through our service user review panels (SURPs).

It is hard to recognise Linda Willis from her description of herself five years ago, when she was diagnosed with vascular dementia.

‘I didn’t want to discuss my condition, or even talk to anyone in case I said something wrong and would be laughed at.’

Linda, now 67, is a very vocal member of our service user review panel (SURP) in Blackwood, Gwent, sharing views on everything from policies and training packages to making museums more dementia friendly.

Fellow member Gavin Watkins, 58, talks about a similar transformation since his Alzheimer’s diagnosis in 2010.

He says, ‘At one time I didn’t want to leave the house but I’ve come out of my shell. It’s completely turned me around.’

Real influence

SURPs provide a way for people with dementia to have a real influence on what Alzheimer’s Society and other organisations do.

Bethan Morris, Dementia Support Worker, says, ‘SURP members have incredible views and experiences, and are able to offer so much knowledge to feed into the development of services.

‘The great thing is that people with dementia on the panel are listened to.’

Denise Saunders, another member of the Blackwood SURP, says that any fears she had about taking part disappeared as soon as she turned up.

Denise, aged 61 and diagnosed with Alzheimer’s four years ago, says, ‘I love going along once a month, I’ve met lovely people there.’

Highlight

In addition to the Society’s work, Blackwood SURP members have had their say on efforts to make theatres accessible and to improve dementia care in Wales.

One highlight was the opening of Cwmgelli Lodge, a specialist centre for younger people with dementia that includes respite and longer term accommodation. SURP members helped to choose everything from carpets to door handles, and they now meet there each month.

Denise says, ‘The new building is absolutely amazing, beautiful – we’ve all picked out our own rooms for when we might need to stay!’

To other people with a diagnosis, Linda says, ‘Focus on the things you can do rather than what you cannot do.

‘Try new things and you will be amazed at what you can achieve.’

Visit alzheimers.org.uk/yoursay to find out more about influencing our and others’ work.

Giving a voice

£55, or a monthly donation of £5, could pay for one person to attend a service user review panel. See alzheimers.org.uk/donate or call 0330 333 0804 (local rate).
Walking together

As people start signing up for this autumn’s Memory Walk events, we speak to one walker whose whole family took part in Leeds last year.

The way Nina’s family got involved in last year’s Memory Walk embodies some of the event’s best aspects – people of all ages coming together to do however much they can to walk for a world without dementia.

Nina, 35, says, ‘There were four generations of the family in Roundhay Park, Leeds for the walk, 12 of us from my grandmother and her sister, both in their 80s, down to the great-grandchildren aged one and four.

‘We all did different amounts of walking according to what we could manage, and afterwards we gathered in the café for lunch.

‘Grandad was brought from his care home to join us in the café, which is one of his favourite places – he still remembers it well and is always thrilled to be there.’

Together as a family

Nina’s grandfather was diagnosed with Alzheimer’s disease in 2009.

‘I live in London, and now when I travel to Leeds to visit my grandparents they’re in two separate places. I stay with my grandmother and I only see my grandfather for an hour or so at his care home in another part of the city.

‘Memory Walk was a really nice way for us to get together as a family and do something positive. The practical support and advice from Alzheimer’s Society is really valuable, and so are the social activities they organise.’

Nina’s family raised over £700 last year and she adds, ‘I hope this will help the Society to keep providing those things – and in the longer term, this disease desperately needs a cure.’

Visit memorywalk.org.uk to find your nearest Memory Walk this autumn, or call 0300 330 5452 (local rate).

Get baking on 16 June

Join in the fun of Cupcake Day – host, bake, buy or just eat to help raise money for the Society.

Get your free cupcake kit from cupcakeday.org.uk

Father’s Day

We have great gift ideas for Father’s Day in our online shop, from bike accessories to ‘man candles’.

Visit the Gifts for him section at alzheimers.org.uk/shop

Personalised jigsaw

Unforgettable.org and Active Minds have developed a range of personalised jigsaw puzzles for people with dementia. Upload an image that will trigger memories for a puzzle of 13, 24 or 35 pieces. £29.99 plus postage.

See www.unforgettable.org/create-your-own-puzzle

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Both sides of the fence

A volunteer in the East Midlands is using her professional and personal experiences of dementia to help provide local Society services.

Pam Freer, who volunteers for the Society in Fenland, has no illusions about the impact of dementia on people’s lives. She was supporting people with the condition, initially in hospital and then social services, decades before her husband’s diagnosis.

Pam, now 71, says, ‘Although I’d worked with dementia for over 30 years in various roles, it was very different being on the other side of the fence.’

Despite her experience and skills, there were times she simply needed to let off steam while caring for her husband of 51 years, who died last August.

‘I had a “swear garden”,’ she says. ‘I used to go to the end of the garden and have a little swear! After that we’d have a cup of tea and things felt much better.’

Determined

Even before her husband’s vascular dementia was confirmed, Pam was determined to put her professional experience to good use after retiring six years ago.

‘I didn’t want to sit at home and I had enjoyed working with people with dementia, so I contacted Alzheimer’s Society’s Fenland office.’

At first the only volunteer at her local group, she is now part of a team whose volunteering means the Society can offer a monthly dementia café as well as fortnightly activity groups in Wisbech, north Cambridgeshire.

‘It’s very rewarding and positive – it makes me get up in the morning. It’s using all the training I had, taking that experience along to the group and sharing it with other volunteers.’

Nice group

People access a lot of information in the dementia café’s relaxed environment, while the activity groups are an opportunity to meet others and have a bit of fun.

Pam says, ‘We’ve got a nice little group of volunteers. Some go straight to the kitchen to get the urn on, others arrange chairs or greet people as they come in.’

She is most animated when talking about the impact of groups on the people who attend them. One man with dementia who didn’t want to leave the house agreed to come to an activity group accompanied by a support worker.

‘The transformation now is unbelievable. He really looks forward to enjoying the group and meeting his friends, and his wife is not so stressed.’

In her own time, Pam also runs a monthly lunch club for people with dementia and carers, helped by another volunteer.

Happy place

Pam’s advice for anyone who is hesitant about attending a local group is simple.

‘Go along with an open mind and you’ll be pleasantly surprised with the laughter and activity. It isn’t doom and gloom – it’s a very happy place.’

Find out more about opportunities to volunteer near you – see alzheimers.org.uk/volunteer or call 0845 504 9300 (call costs vary).
I managed a Leeds charity for older people before joining the Society just over a year ago, and the experience made me realise how many living in our communities are socially isolated. If someone has dementia, isolation can make ‘continuing as usual’ so much harder.

Side by Side, now in the third year of its three-year pilot, has the potential to change the lives of a great many people. It enables people with dementia to continue doing the things they have always enjoyed, supported by a trained volunteer.

Side by Side is already having an impact across Worcestershire, one of our pilot areas. Our amazing volunteers are enabling people with dementia to do both ordinary and extraordinary things.

One gentleman who used to play and coach rugby has been invited to watch a match at Sixways Stadium with his volunteer, hosted by Worcester Warriors. His wife says he looks forward to his weekly Side by Side excursions, regaining some of the confidence he lost after his diagnosis.

A lady who used to be a keen knitter but hadn’t felt like doing it for while has taught her volunteer to knit during their weekly visits. We are now looking at opportunities to enable her to teach other people, perhaps in a small group.

The outcomes achieved over the past months show that Side by Side really does make a difference, reducing isolation and enabling people with dementia to regain confidence to live independently.

For more about Side by Side, see alzheimers.org.uk/sidebyside
A partnership between Alzheimer’s Society and Helm Housing was recognised at the recent CIH Housing Awards in Belfast. Helm, a non-profit housing association, received the Chairman’s Award for its commitment to dementia-friendly communities in Northern Ireland.

Helm Housing owns Hemsworth Court, a supported housing scheme for people with dementia, and made a commitment to becoming more dementia friendly last year. A total of 94 staff members became Dementia Friends between February and April 2015, and seven also completed two-day training to become Dementia Friends Champions.

Pamela Frazer, Dementia Friendly Communities Support Manager, said, ‘Helm Housing has progressed greatly in its knowledge of dementia and commitment to those tenants living with the condition and their families, making a real difference in the support offered. Alzheimer’s Society is proud to work in partnership with them.’

Cardiff-based Vista Retail Support is aiming to raise £3,000 for Alzheimer’s Society by September. The IT firm has chosen us as its charity of the year, with staff taking on a range of challenges to support people affected by dementia.

Richard Cottrell, Vista’s Managing Director, said, ‘We hope the partnership will not only provide vital funds but also provide an opportunity to raise awareness.’

Earlier this year the Good Life Festival in Salford celebrated the different ways people with dementia can continue to live well. The event was planned and delivered by people affected by dementia, featuring activities including friendship groups, singing, dancing, art, sport, gardening and holidays.

The Society’s Beth Luxmoore, a member of the event’s planning group, said, ‘The whole day was a great success, and achieved our aim of inspiring people who were recently diagnosed to try new things that could help them to live well.’
Dementia Connect – the easy way to find support near you

Dementia Connect is Alzheimer’s Society’s online services directory for anyone affected by dementia in England, Wales and Northern Ireland.

It’s the most comprehensive online directory of its kind, with over 4,000 listings of local information and support services that can help people with dementia, their families and carers to live well.

Use our simple search to find services that are nearest and most relevant to you today.

alzheimers.org.uk/dementiaconnect
Next steps

- Raise money for vital research and services on Cupcake Day, 16 June – see cupcakeday.org.uk
- Visit www.joindementiaresearch.org.uk to register your interest in taking part in dementia research.
- For our factsheet Risk factors for dementia (450), see alzheimers.org.uk/factsheets or call 0300 303 5933.
Understanding risk

Society-funded research is finding out about the very earliest stages of dementia. Luke Bishop talks to a man whose father has dementia and who decided to take part in the study.

Malcolm Weller, from Ealing in west London, was keen to participate in the Society-funded PREVENT research project when he found out about it in 2012.

Malcolm, now 54, was at that point looking after his father Barrie, who had come to stay to recuperate from an operation. It soon became clear that his father had difficulties with his memory, balance and spatial awareness.

Barrie was diagnosed with vascular dementia, later amended to mixed dementia with Alzheimer’s disease. At the memory clinic Malcolm was offered the chance to participate in the PREVENT study.

He explains, ‘The doctor at the clinic, Dr Brian Corridan, was one of the people who was helping to set up the PREVENT project and asked us if we wanted to be involved in any studies. My dad wasn’t interested but I said yes.

‘The project is all about trying to find some of the markers that give an indication of potential risk of acquiring dementia in the future.’

Unusually for dementia research, PREVENT is studying people in their 40s and 50s to understand what changes take place in the body at the very earliest stages of the condition. The aim is to identify factors that increase someone’s risk and then to reduce this risk.

Like an MOT

The PREVENT study began at Imperial College London – where Malcolm takes part – before expanding to sites in Edinburgh, Oxford and Cambridge.

Malcolm says, ‘I have now been through two assessments, one of which was earlier this year and the first two years before that.

‘They take blood samples and test them for various things, they do cognitive tests, they test lung function and strength, your height and weight, take samples of your saliva and urine and also do an MRI scan to see what the brain looks like.

‘It is kind of the equivalent of having an MOT carried out.’

This has also led to Malcolm becoming involved in other research projects, such as the Approaches to the Communication of Alzheimer’s Disease Risk (ACAR) project led by the University of Cambridge.

This study, in which Malcolm was involved in January 2016, covered interesting ethical and personal dilemmas, such as how much information can and should be given to people regarding the likelihood of developing dementia.
Health and lifestyle
Malcolm has asked researchers for the results of some of the tests he has undergone in order to better understand his personal health, if not necessarily his risk of developing dementia.

He says that participation in research has also encouraged him to think more about his lifestyle, particularly diet, activity and exercise.

‘Based on the evidence of previous studies there is a theory that certain lifestyles can decrease your risk. For example, eating oily fish may improve your brain function and decrease the risk of developing Alzheimer’s disease.

‘Part of the study also goes into those lifestyle areas, so they ask you about the types of food that you eat on a regular basis. They take notes on your diet, hours of exercise per week and so on.

‘I think that, when you know that certain types of behaviour increase risk of dementia, it does encourage you to get up and go for that run, for example. It has certainly changed my perception in that respect.’

Involvement
Since joining the PREVENT study, Malcolm has become involved in its participants’ panel, which provides feedback about how the project is run. The panel was consulted on a membership scheme to encourage fundraising for the project, as well as ongoing engagement with participants and the public. This scheme was launched earlier this year.

Crucially, Malcolm believes that participation in the research has allowed him a greater appreciation of what his father, who is now living in a care home, is going through with his dementia.

Unusually for dementia research, PREVENT is studying people in their 40s and 50s to understand what changes take place in the body at the very earliest stages of the condition. The aim is to identify factors that increase someone’s risk and then to reduce this risk.

‘Through taking part in the study I have learned a lot about dementia. For example, my wife got me a book to read about how to react with a person who has dementia so as not to exacerbate the problems that they are going through.

‘There was a time when he was living with me when I would be working in one room and my dad would come in and ask questions. I would give him the answer and he would go away and then come back again and ask the same question.

‘I’ve realised that, at such times, it is important not to get too upset and to answer the question in the same way, because if you get irritated then that can create quite a big problem as he wouldn’t then understand why someone is getting annoyed with him.’

Improved relationship
Malcolm says that his relationship with his father has improved as his understanding developed and their circumstances changed.

‘All the time he was staying around my house, our interactions were limited to catering for his needs. He would repeat questions quite regularly and so our relationship was getting a bit strained.

‘Now when I visit him in the care home I spend a few hours with him there, and it is nice and enjoyable to interact with him. We go through old photograph albums and poetry books.’

By taking part in the PREVENT study, Malcolm and his fellow participants are helping to make sure that we will one day not only understand a person’s risk of developing dementia, but also what they can do about it.
Malcolm Weller agreed to take part in dementia research after his father Barrie was diagnosed with dementia in 2012.

The PREVENT project is studying people in their 40s and 50s to understand what changes take place in the body at the very earliest stages of the condition.

Malcolm, now 54, was interested in the study because it aims to identify factors that increase a person’s risk of developing dementia.

He has been through two assessments as part of the study, involving brain scans, tests of his lungs and taking blood, saliva and urine samples.

Since taking part in the project, Malcolm has become more aware of his health and lifestyle, and has a greater understanding of his father’s condition.
Margaret Pigott often popped out leaving her husband Trevor at home, until he slipped out of the house and sparked a full-scale police search.

‘Trevor has mixed dementia – Alzheimer’s and vascular dementia – but he had never gone missing before, so I was naïve enough to think he would be fine,’ says Margaret, 63.

‘I only went out for an hour to see friends for coffee but when I got back the window cleaner said, “Where’s Trevor?”’

‘I looked all over the house, then I got in the car and started driving, but after about quarter of an hour I thought, “This is crazy,” and went to the nearest police station.’

Door to door
Rotherham police launched a manhunt involving a door-to-door search and a police helicopter. Trevor, then aged 69, was found four hours later in the grounds of a hospital that is a 15-minute walk from their home.

‘He told the police he was looking for me, and I think he went to the hospital because we had been there for appointments,’ says Margaret.

‘While he was missing I felt numb and tried to stop myself fearing the worst, but when the police found him I burst into tears I was so relieved.’

Although the officer assigned to Margaret during the search had been kind, she found it challenging to provide lots of facts when she was so anxious.

So Margaret was very interested when she heard about a scheme to support people whose vulnerable relatives might go missing.

Herbert Protocol
The Herbert Protocol was established in South Yorkshire by Rotherham Dementia Action Alliance and the Society working with local police.

Using the protocol, people provide information about a person who may go missing to help in any search. This includes details about medication, interests, previous addresses and workplaces, as well as a recent photo.

‘It is hard to bring information to mind quickly when you are really worried,’ says Margaret.

‘People might be daunted by the form but it is reassuring to know you have all the information when it’s most needed.’

Liz Hopkinson, Services Manager at the local Society, says the protocol was devised after police told her about difficulties gathering information from distressed relatives.

‘The police said carers of missing people were so stressed they couldn’t remember facts like old workplaces and addresses,’ says Liz.

Precious minutes
South Yorkshire’s protocol is based on one developed in Norfolk, which was designed to help police find people who went missing from care homes. It included input from carers like Eric Turner, 69.

Eric’s wife Carole has posterior cortical atrophy, a rarer form of dementia also known as Benson’s syndrome.

He says, ‘When someone goes missing you can’t think straight but this way all the facts are laid out already, saving the police precious minutes.’

Although people are advised to carry the form with them, Eric suggests taking a photograph of it with your phone that you can email to the police.

He advises, ‘Don’t forget to update the protocol if there are any changes like hair colour or new glasses.’
Safety blanket

Rob Moore, Director of Home Instead Senior Care in Doncaster, says all his clients with dementia have completed a protocol.

‘It provides reassurance to families and is a safety blanket that allows people to keep their independence longer,’ he says.

‘It means that people with dementia can still go out for a walk or pop to the shops, and if they do go missing there is a plan so people can be found as quickly as possible.’

Superintendent Paul McCurry at South Yorkshire Police says the protocol – adapted for people living at home as well as in residential care – has helped them find a number of people.

‘When your loved one goes missing you may be feeling traumatised and unable to bring information to mind,’ he says.

‘And the last thing you want is to have police officers asking you lots of questions when you want them to be out looking for your relative.

‘Hunting for someone can be like looking for a needle in a haystack, but if we have already identified locations this has got to pay dividends.’

Easy set-up

In the two years since it was launched, thousands of people with dementia in South Yorkshire have been encouraged to make use of the protocol.

It has been taken up in other areas, sometimes with their own version of the form.

‘This is so easy to set up,’ says Liz. ‘There is no cost and it involves minimal input but has a massive impact.

‘Carers are reassured they have all the information they need so the police are able to start searching within minutes. If someone goes missing in poor weather, this could save someone’s life.’

Next steps

• Download the South Yorkshire Herbert Protocol from www.southyorks.police.uk/help-and-advice/herbert-protocol

• For our factsheet Walking about (501), see alzheimers.org.uk/factsheets or call 0300 303 5933 (local rate).

• Visit alzheimers.org.uk/fundraise or call 0330 333 0804 (local rate) to see how you can help raise money for vital services.

Quick read

A South Yorkshire scheme is helping missing vulnerable people to be found quickly, by putting useful information in one place for when it might help a search.

The Herbert Protocol, originally devised in Norfolk for people in residential care, was adapted to include people living at home as well.

Margaret Pigott, who had to call the police when her husband went missing, says it is reassuring to have all the information together for when it may be needed.

Superintendent Paul McCurry says the protocol allows them to identify places the person might have gone.

Liz Hopkinson, Services Manager at the local Society, says the protocol could help to save someone’s life, particularly if they go missing in poor weather.
Living Words, an organisation led by Susanna Howard, has been working with people with dementia since 2007. Team members encourage free expression, enabling people to be heard and understood even when communication seems lost.

Through residencies in day centres, theatres and care homes, Susanna and her small team of artists have honed a special way of working one-to-one with people. Over time, they listen to, talk with and – most important of all – hear the person they are with. They give their undivided attention, recording the person’s words exactly as spoken.

Now, nearing the end of a residency in north-west London, Susanna and her colleagues present these words back to the people they have worked with, poem-like and in the form of books.

Anticipation
The lobby of the Butterworth Centre, a continuing care unit based at the Hospital of St John and St Elizabeth in London, is being made suitable for the presentation. Residents, staff and visitors arrive and gradually settle. The atmosphere is one of anticipation.

Quiet words are exchanged, a helping hand extended, reassurances sought and given, and there is a sudden uncensored outburst, heartfelt and difficult to interpret.

Drawn out
Attending is Angela, whose husband of 40 years, Michael, died recently. He lived at the centre for the last two years and took part in the project, and is moving to observe. This is not about who they were but who they are, and how they are feeling, here and now.

‘Our work is not concerned with recalling memories so much as expressing feelings,’ says Susanna. ‘Too often people just see what the person with dementia cannot do, compounding their isolation. We need to go deep with them, and others need to see that this is still possible.’

‘Others’ include the professional carers the Living Words team work alongside and for whom they run workshops.

Shown the way
As well as presenting people’s words at the event, Living Words gives certificates to staff who attend their workshops, recognising their work and commitment to develop the project’s legacy. Atumanni, the centre manager, expresses his delight.

‘This has exceeded my expectations. I didn’t think this level of engagement was any longer possible for my patients. I am so pleased.’

His colleague, Christina, adds, ‘They have shown us the way. We think they live in another universe, but to hear from our patients in this way, in words that resonate with us all, is very moving.’

‘I’m very touched, reading the things Michael said,’ says Angela. ‘And pleased to see the staff recognised for all that they do. ‘Perhaps what most came across was Michael’s concern for other people. You see, he never thought there was anything much wrong with him, but he cared about the people living here.’
Communication can become increasingly challenging as dementia progresses. Andrew Bence finds out about a project that helps people to be heard.

Quick read

Living Words works with people who have dementia to encourage their expression and others’ understanding. They recently completed a residency in a north-west London continuing care unit.

Susanna Howard and her team work one-to-one with people, recording their words and presenting these back to them in the form of poems and books.

Angela, whose late husband Michael took part in the project at the Butterworth Centre, was initially sceptical but was touched by hearing his words in this way.

The work focuses on who the person is and how they are feeling in the here and now.

Staff at the centre say the project has shown them what levels of engagement are possible, even when a person’s dementia is advanced.

Their own words

Michael: ‘I’m very pleased. I’m very glad we’re going this evening. After too many years. Rather a trick of a life. Extraordinary isn’t it, this house.’

Jennifer: ‘Am I a dream? No, I am here.’

Peter: ‘My mind seems to have gone. For a while, the moment seems to be lost for words. I suppose it’s worked out alright.’

Next steps

• Visit www.livingwords.org.uk for more about Living Words.

• For our factsheet Communicating (500), see alzheimers.org.uk/factsheets or call 0300 303 5933 (local rate).

• Go to alzheimers.org.uk/volunteer or call 0845 504 9300 (costs vary) for local opportunities to volunteer.
Accepting that not everyone with dementia will be eligible for NHS Continuing Health Care (CHC) funding, there are some real contradictions and issues with how that eligibility process is being managed – and no recognition of the impact of removing funding with 28 days’ notice, in an eight-person 24-hour care team!

My family featured in the April/May magazine. Using the budget that my mother Jean became entitled to, we have set up what many professionals have cited as a wonderful team providing fantastic care, liaising closely and regularly with all the relevant agencies.

It’s not been easy, but it has given her dignity and a sense of who she is, and brought some amazing carers back to the workplace who’d become disillusioned with other forms of care, and the budget is used in a completely transparent way.

The problem is that the clinical commissioning group (CCG) has decided that Mum no longer has a healthcare need, just a social care one, alongside the carefully chosen caveat description of ‘incidental’ nursing needs.

My mother’s healthcare needs are continuing, and they haven’t got any better. They have, in fact, become progressively worse and we have adapted accordingly. I can see how needs can become described more social versus health, under the rules. But where the care provided is effective in managing the needs and risks – but not permanently reducing or removing them – this should not be allowed to diminish the need.

In my experience it seems to be built in to the CHC process to identify the lowest possible score that can be given to any domain, with pressure to agree it at that lower level. If you are providing excellent care with a familiar care team, this has a penalisable effect. The value of the promptness and skill of carers familiar with the person and carrying out one-to-one care is effectively reducing the individual situation to being ‘easy and simple’.

Further, my experience of Alzheimer’s is that it is punitively treated in comparison to the impact of more obviously physical conditions because ‘we don’t really know what is going on,’ again resulting in lower domain scores. For example, behaviours are treated as not so impactful to the individual, and psychological and emotional effects are largely discounted.

In the longer term the lines between mental and physical health, and social and health care in particular, need to merge. Today, they are being abused in the way health decisions are being made.

For the here and now, I remain hopeful that I can appeal to the value of ‘fairness’ within the CCG, not least for the courageous strength shown by my mother, who is considered to be in end of life.

Mark Chipperfield, Hertfordshire

Congratulations to Mark, who will receive a bouquet of flowers.

Many people are surprised to find that care provided for a person with dementia, who may have other complex conditions too, will not usually be funded by the NHS.

CHC is a complete package of care funded by the NHS. It is awarded to people who are considered to have a ‘primary health need’ and can be provided in any setting including the person’s home, as we have seen in Jean’s case.

There is an important distinction between health and social care. If someone has nursing care needs but these are assessed as being only ‘incidental or ancillary’ to their social care needs, then they will not be found eligible for CHC funding.

Alzheimer’s Society believes that the assessment process and tools that are used to decide who is eligible for CHC funding discriminate against people with dementia. National guidance is not applied or interpreted consistently across the country. We continue to try to influence policy and practice to change this.
Challenging a decision not to award CHC funding is a lengthy and difficult process that requires persistence, but it is worth pursuing if you feel you are eligible.

For our booklet When does the NHS pay for care? (813), visit alzheimers.org.uk/publications or call 0300 303 5933 (local rate).

Page footers
I am glad to be receiving Living with dementia magazine regularly now, and I have already picked up quite a bit of valuable information. May I make a suggestion?

As my limited storage space means I will not be able to ‘file’ each issue, I cut out articles or pages that are of special interest.

It would be a real help if, at the foot of each page, next to the page number and magazine title, you could add the month of issue, for example April/May 2016.

Many other periodicals that I receive do this, and it is most helpful not to have to constantly write the date of latest known currency of information on every separate piece I cut out.

Many thanks for your consideration.
David Longley, Kent

It is always good to hear about the different ways in which people make use of their old magazines, whether archiving them for future reference or passing them on to others.

It is also very helpful to get this kind of feedback from readers, and although we can’t promise that we’ll be able to implement every specific suggestion, we will definitely take this into account as we continue to develop the magazine.

Alzheimer’s Society is committed to increasing the number of ways in which people affected by dementia can influence our work.

Being part of our new Virtual Advisory Board allows you to influence our decision making at board and senior levels, ensuring that our work is informed by the challenges you face.

For further information about this opportunity, including a role description, please ring 020 7423 7315 or visit alzheimers.org.uk/virtualadvisoryboard

Your turn
Tell us what you think – write to Magazine Editor, Alzheimer’s Society, Devon House, 58 St Katharine’s Way, London E1W 1LB or email magazine@alzheimers.org.uk

Letters for the August/September issue to arrive by 8 July. Views expressed are not necessarily those of Alzheimer’s Society. Letters may be edited.
Carers’ guilt

No matter what choices carers make as dementia progresses, they often have to deal with feelings of guilt and regret.

Caring for a person with dementia brings many practical and emotional challenges. Family members and carers may feel guilty, even when they are making good and careful choices.

It is difficult if a person with dementia denies that anything is wrong and refuses to see the doctor. It can also be hard if someone is behaving in a challenging way because of their dementia. Making difficult decisions, such as having to arrange residential care for a person with dementia, can also mean that carers struggle with feelings of guilt.

Guilt monster
On Talking Point, people often refer to this as the ‘guilt monster’. Even when making the best decisions for parents or spouses, carers may have to deal with powerful feelings of guilt and regret.

It can be difficult to share how you are feeling, especially if family members don’t understand your perspective, or may be critical of decisions without knowing the full story or your situation.

On Talking Point, our online community, there are forums for people who are dealing with all stages of dementia – from getting a diagnosis to supporting a person with advanced dementia. There is also a members’ only area for people to discuss particularly difficult or sensitive topics.

Sharing
Talking Point members have used the community to ask other people affected by dementia about dealing with feelings of guilt or anger, how to cope when someone is in denial about their condition, and whether they should be considering residential care for a loved one.

Having a place to share your experience with other people who are in similar situations and may understand how you are feeling can make a huge difference. Other Talking Point members can suggest things that might be helpful and offer support. Talking Point is free, open day or night, and you just need an internet connection to take part.

To join in, visit alzheimers.org.uk/talkingpoint

For our factsheet Carers: looking after yourself (523), see alzheimers.org.uk/factsheets or call 0300 303 5933 (local rate).

Eating and drinking Q&A session

There are monthly Q&A sessions for Talking Point members in the community’s chat room, featuring people with specialist areas of expertise. You can email questions in advance, and a transcript of the session is available afterwards.

The next Q&A session will be on eating and drinking, with Gemma Jolly, Health and Wellbeing Knowledge Officer, at 3–4pm on 23 June. Visit alzheimers.org.uk/talkingpoint
Sweet and savoury

Being included in planning meals and in buying, cooking, eating and clearing up after food is something that many people with dementia enjoy.

Preparing meals can be an important part of a person’s identity, and breaking activities down into steps could help someone to take part.

A special activity could involve looking at a range of fruit or cheeses, which the person might also help in choosing and buying. These could be labelled and cut into small pieces for tasting, and the different colours, textures and aromas discussed. Whole fruits can be handled and smelled, including unusual varieties. Cheeses might be enjoyed with chutney or pickle, and washed down with water, juice or wine.

It can also be fun to recall sweetshop memories. Use a variety of retro sweets as prompts to reminisce and share favourites. If someone didn’t go to sweetshops, perhaps something else could be as evocative – for example, Indian sweets.

More ideas are included in our guide Taking part: activities for people with dementia, currently at a reduced price of £15 plus postage via our online shop – see alzheimers.org.uk/shop or call 0844 245 1175 (call costs vary).

Sharing personal information when someone has dementia

Accessing and sharing information: Acting on behalf of a person with dementia is a free publication that provides practical advice on handling a person’s personal information.

The publication outlines your rights and covers common situations, eg managing medical records, bank or credit card details and utility bills.

For more information and to order your copy online, please visit alzheimers.org.uk/sharinginformation

Alternatively call 0300 303 5933 or email orders@alzheimers.org.uk and quote product code 882.
Clamshell phone

The PhoneEasy 612 is a popular phone for people who want something that’s straightforward to call and text with, and which can also take pictures and be used as an alarm.

It is a durable design with a large keypad and screen. In addition to the usual keys, it has three marked A, B and C that can be set up to call a person’s most used numbers.

Most of the group liked this phone, including the fact that a start-up wizard helps you to customise and set it up when you first use it.

Dave and Alan both liked the phone’s simplicity. Nigel wasn’t surprised that this is Doro’s bestselling phone – he also uses a clamshell phone because it’s easy to open, even with one hand.

Janice was impressed by the phone’s long battery life, lasting for over 500 hours on standby.

Reassuringly, it has an emergency assist button on the back that can be programmed to alert up to five contacts if you ever need help.

Smartphone

The Liberto 825 is a smartphone that can use all the usual apps for checking anything from where you are to what the weather forecast is, or for keeping in touch through Facebook, Skype or email.

As Stan pointed out, referring to how his children use their smartphones, ‘You can do everything on them except cook food!’

Some, including Tony and Michael, were accustomed to smartphones and made good use of them, while others were less confident.

However, this phone is designed so that you only need to learn the aspects that you actually want to use, with a ‘coach’ popping up to help when you do something for the first time.

As well as buttons for frequent contacts, you use three buttons – call, view and send – to do most things. These lead you through simple step-by-step processes using clear language.

Trying these out, Stan agreed that they were very straightforward and easy to understand.
The smartphone also has an emergency assist button on the back, which can send the phone’s location to up to five people along with an alert message.

Simple phone
The Secure 580 is a very simple device with four large buttons instead of a keypad, which can be programmed (and labelled) to call four specific numbers. It cannot make calls to anyone else, and you can choose for it to only accept calls from a ‘white list’ of up to 20 numbers.

Although it is not a smartphone – and so cannot be used to access a map – the device’s emergency assist button can still be set up to send the phone’s location to up to five pre-programmed contacts.

An assigned relative or friend can also message the device to check its location at any time if they are worried.

It is designed with a good grip and long battery life.

Janice, showing everyone the phone she keeps at the bottom of her handbag but doesn’t even switch on, said the Secure 580 sounded very useful to her.

Steve also preferred this device, though David and Ray were less sure, saying they would probably want a family member to help pick one for them.

The PhoneEasy 612 is £66.67, the Liberto 825 is £208.33 and the Secure 580 is £108.32 – all plus VAT, though people with dementia or other long-term conditions do not have to pay VAT on these products.

Have you used these or similar products? Email your experiences to magazine@alzheimers.org.uk or write to the address on p27 so we can improve our online shop range and feed back to designers and manufacturers.

For our full range of helpful products, see our new Daily living aids catalogue or visit alzheimers.org.uk/shop
Your answers

## Continence problems

Talking Point members and readers share advice on getting the right kind of help and products to deal with incontinence.

‘When my husband first started having “accidents” he was so mortified. So I picked a quiet time and brought him to Tesco and showed him that this was such a common problem that you can just buy pads in the supermarket! Not only that, but so many people suffer the same problem that the supermarket even does their own brand. He felt a lot better about it once he realised that there must be thousands more people with the same problem.’

**LadyA**

‘Try to persuade the incontinence nurse to let you have the pull-on pants. Mum got into the habit of taking her pants off and wetting the bed. Onesies kept the pants on and were only £8. They wash and dry quickly and Mum likes the feel of the plush fabric, particularly if I warm them in the airing cupboard. Wet wipes are a godsend but don’t flush them down the WC as they can easily block drains.’

**John in London**

‘My husband has been incontinent for some time. I use three to four pants with built-in absorbent pads every 24 hours. The NHS provides half the quantity I need. I put two pants on at a time with a booster pad inside the first. Changing is made easier because I just tear the inside pants off down the sides and remove the booster pad, place a new booster pad into the remaining pants.’

**Bisham**

‘My husband’s fear of incontinence is the real problem – he is often afraid to leave the house. We have always been within reach of a disabled WC, for which we have a Radar key (I carry an emergency bag with rubber gloves, wet wipes and clean clothes). It’s so important to keep calm about the problem, and to keep smiling and to hide the fact that bottom-wiping is my least favourite occupation as a carer.’

**Moseley B13**

‘I give my husband incontinence pads – pants – to wear and dispose of when they are wet, I wash his trousers and his pyjamas daily as the pads are not leak-proof, I have bought bed pads online which are waterproof and do not feel wet, and I have ordered similar pads to use on chairs. The incontinence is more worrying, time-consuming and leads to more crises than any other aspect of his dementia.’

**Irene in Oxfordshire**

‘Faecal incontinence can be triggered and/or exacerbated by trying to address an underlying, and possibly longstanding, tendency towards constipation. For some people the use of medication or too big an intake of insoluble fibre can lead to a seesawing between constipation and diarrhoea that leads to incontinence. Eating oats (a soluble fibre) can help to deal with the problem in a gentler way that can reduce the likelihood of “accidents”.’

**stanleypj**

‘The pads provided by our incontinence clinic are not the most absorbent available. It does depend on how well they are fitted, and for that I rely on agency staff who are inconsistent. My other half has a habit of taking them off on her first trip to the toilet and then forgetting to get up when she needs to later in the night. Trying to refit pads at 1am when you are both half asleep is not easy.’

**nae sporran**

‘Our continence clinic provides pull-up pants as standard. No problem with the quantities except that they deliver four months’ supply at a time. The clinic offer different sizes but only one style. These are fine during the day but don’t fit my wife well enough to stop leakage at night, so we buy night-time pants from a big name. For disposal I use nappy sacks, which are really meant for babies’ nappies.’

**BeardyD**

For our factsheet Managing toilet problems and incontinence (502), visit alzheimers.org.uk/factsheets or call 0300 303 5933 (local rate).

See the full discussion thread at alzheimers.org.uk/talkingpoint

**Next issue**

Do you have tips about coping with warmer weather? Email magazine@alzheimers.org.uk or write to the address on p27.
Driving is a skill that many people hone over a lifetime, but which dementia can begin to undermine.

Apart from being useful, especially in areas where public transport is limited, for many people being a driver is also an important part of their identity. This can make discussions about it very hard.

**Responsibilities**

Your husband was right to tell DVLA (or DVA in Northern Ireland) about his diagnosis – not telling them would have been illegal.

If an assessment at a driving centre has led to DVLA revoking, or cancelling, his driving licence, it will be because they think he is not safe to be on the road.

If anyone tells DVLA that your husband is still driving, their enforcement team can follow it up with the police.

Occasionally someone might not accept the DVLA’s decision, perhaps because they don’t accept their diagnosis or underestimate the impact that dementia has on their driving.

However, continuing to drive like this is illegal. It means the person is uninsured, and puts them and others at risk of an accident.

**Persuasion**

It is best if you can persuade your husband to see that he needs to stop. Could his GP do this – sometimes hearing it from a professional is more effective?

Practicalities aside, this will need very careful handling because he will sense it as a loss. Has he had near misses or minor scrapes which might help him to see that he’s not safe? How would he feel if he had an accident and hurt someone?

Perhaps make a list of the benefits of not driving and practical ways you could both manage.

**Acting in his interests**

If you can’t convince your husband to stop driving, you may act without his consent if it is in his own interests and he can’t decide for himself.

Can you park the car somewhere so that it is not a constant reminder? Some people decide they have to hide the car keys. It’s best to use these as last resorts, as they can cause family friction.

Whatever you do, remember that driving for many people is much more than a way to get from A to B.

For our Driving and dementia (439) and Making decisions and managing difficult situations (484) factsheets, see alzheimers.org.uk/factsheets or call 0300 303 5933 (local rate).
When someone you love has dementia

Readers comment on a book that speaks to carers, and we invite you to read What the hell happened to my brain? for next issue.

When someone you love has dementia, by Susan Elliot-Wright, was first published in 2010 and a new edition has been released this year. The author is a novelist who has also written a range of non-fiction books on health-related subjects.

Janet Baylis, Manager of our Dementia Knowledge Centre, says, ‘As the title makes clear, this slim book is not written with the person with dementia in mind as its reader.

‘I would suggest it as an introductory guide for people with limited knowledge of dementia who want an overview of what life as a carer may be like. This could be at the point of seeking help or when going through a dementia diagnosis as a carer, relative or friend.’

Carmen Jones, a former carer in Buckinghamshire, says, ‘I read the book with great interest – it brought back a number of my own experiences. How much easier life would have been, if I had read this useful little book before life sent us along the “dementia road”.’

Practical

The book introduces different kinds of dementia before looking at diagnosis and options for treatment and care, including residential care. Chapters are short, factual and written in a straightforward way, and some case studies are included which tell personal stories.

Carmen says, ‘This book is well written, clear, concise, yet with sufficient detail to cover all aspects – practical and financial as well as emotional. The sections are linked by references, and a number of pertinent examples make the subject more tangible.’

However, another reader found it to be on the wordy side and noted a lack of any illustrations or photographs to complement the text.

She adds, ‘More personal stories would be welcome and make it easier to read.’

There’s a lot of useful practical information here but using checklists, more tips and action points could better encourage carers to translate some of the ideas into practice.

Empathy

Readers had differing views about the tone and language of the book.

Carmen says, ‘I like the gentle empathy that is evident throughout, and the fact that it is not too long – a carer rarely finds time or energy to indulge in reading.’
Another former carer thought that this empathy was directed more at carers than people with a dementia diagnosis, taking issue with some of the language used, particularly in chapters about coping with practicalities.

She says, ‘The author talks of “problems” rather than “challenges”, and some of the words used could grate and show a lack of empathy for the person with dementia – terms like “odd behaviours” and “wandering” instead of walking.’

Despite this, Carmen concludes, ‘I would definitely recommend this book to someone at the beginning of an unexpected journey with dementia, as it is full of handy tips and references.’

When someone you love has dementia by Susan Elliot-Wright (Sheldon, 2016), 218 pages, £8.99, ISBN: 9781847094032.

Recommended by Reading Well Books on Prescription for dementia (www.reading-well.org.uk) and widely available in libraries as well as our online shop – alzheimers.org.uk/shop

Your turn

For the next issue, we invite you to read What the hell happened to my brain? by Kate Swaffer (Jessica Kingsley, 2015), 304 pages, £13.99, ISBN: 9781849056083.

Let us know what you think of this book by 6 July so we can share it in our next issue – email magazine@alzheimers.org.uk or write to the address on p27.

We have five copies to give away – email magazine@alzheimers.org.uk or write to the address on p27 by 22 June quoting ‘What the hell’ for a chance to win one (see p38 for terms and conditions).

Do you care for someone living with dementia?

Nine in 10 carers experience feelings of stress or anxiety several times a week, yet many are unable to access the help or support they deserve.

If this sounds familiar, then you may be eligible to take part in the UK’s largest research study of online support for carers of people with dementia.

Find out more at www.caringformeandyou.org.uk

This study is funded by Alzheimer’s Society with support from Nominet Trust, Stavros Niarchos Foundation and IAPT National Programme.
Life with Ma
Dilly’s story continues

I’m wondering whether Ma’s fairly full-on life does prevent her dementia from progressing too fast? That and the donepezil, of course.

A recent wedding has certainly kept her on her toes – starting with an all-night journey with the Northern branch of the family, arriving at the venue at 7am. Being surrounded by familiar people helps her to keep grounded in what must be a confusing place.

Her way of dealing with it was not to venture too far unless required. As ever though, she seems to thrive on chatting away with wedding guests she’s never met before – though maybe she feels she has? Her social skills remain intact.

She had a part to play at the wedding, but as ever things come as a complete surprise to her. Many months back when the wedding was being planned, she suddenly recited the first few lines of The owl and the pussycat, having learnt the poem as a child. This was our cue to include her reading in the ceremony.

Suddenly asked to recite in front of a hundred guests, she was a bit shocked but read out the whole poem, even adding the right wicked emphasis!

These days she seems to live in the moment, and is finding it harder to recall events, cheerfully admitting, ‘I can’t remember.’ When in doubt, she sits on her bed and does her crosswords – a safe haven for her. She thrives on having a job to do, so we’re trying to keep it that way.

Dilly

Dilly, a daughter-in-law
(continued next issue)
Join Gina and become a Dementia Friend today. Visit dementiafriends.org.uk
Winners and answers

Key finder and fobs competition
Our April/May competition was won by S Carson in Cheshire, and the runners-up were R Campen and D Williams in London, M Chipperfield in Hertfordshire, D Clery in Kent, E Kenny in Liverpool and N Sultan in the Vale of Glamorgan.

Answer: Nelson Mandela was given the ‘keys to the city’ of Leeds in 2001.

Love giveaway
The five readers who won a copy of When someone you love has dementia by Susan Elliot-Wright were B Green in Solihull, J Higgins in Cheshire, C James in Bedfordshire, L Kirkham in Sheffield and A Lee in London.

Doro phone competition
We have a Doro PhoneEasy 612 (see p30) for one lucky winner drawn from correct entries received by 8 July.

What proportion of adults in the UK now use a mobile phone?
• Over 90 per cent
• 80 to 90 per cent
• 70 to 80 per cent

Send us your answer along with your name, address and telephone number for us to receive by 8 July – email magazine@alzheimers.org.uk or post to Magazine Editor, Alzheimer’s Society, Devon House, 58 St Katharine’s Way, London E1W 1LB.

See p35 for our woman&home competition.

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.

For the Loc8tor Lite key finder and key fobs, see our online shop at alzheimers.org.uk/shop
Are you looking for information, advice or support?

If you or someone you know are worried about or affected by dementia, Alzheimer’s Society is here for you.

Turn to us for a range of information and support for anyone affected by dementia.

‘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

Talk to us
Our National Dementia Helpline can provide information, support and guidance. Call **0300 222 1122** (national rate or less) 9am–8pm Monday to Wednesday, 9am–5pm Thursday and Friday, 10am–4pm at weekends or email **helpline@alzheimers.org.uk** for Live Online Advice and other information.

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

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

Support near you
Use our online services directory Dementia Connect to search by postcode, town or city to find information about services and support groups in your local area. **alzheimers.org.uk/dementiacomment**
All things cupcake!
Check out our new Cupcake Day apron and baking range

Every purchase you make helps fund Alzheimer’s Society’s work, supporting people living with dementia and their families, and getting one step closer to a cure.

Shop online alzheimers.org.uk/shop
or order over the phone 0844 245 1175
(calls cost 5p per minute plus your usual network charges).

Leading the fight against dementia
Alzheimer’s Society