Remember the person

Advice on moving into care (7)
To Spain and back (12)
Explaining dementia to children (16)
With the new coalition government’s budget announced, there can now be no doubt we are entering a period of austerity, and the impact will start to affect us all. The cuts in public expenditure at a local level will be felt acutely across all public services, but particularly within social care budgets.

This is just at the time when the country is responding to the National Dementia Strategy and there is an improved understanding of what people with dementia and their carers need to achieve the best quality of life possible.

Clearly, these needs are not going to diminish and numbers of people needing support are growing. The Society, along with other charities and service providers, will be required to do much more with fewer resources, and will need to show how things can be improved, demonstrating real value for money.

As never before in our history, we will need to work together with other organisations to find workable solutions. We need to ensure that people with dementia and their carers do not keep missing out and facing discrimination, and that they receive the vital help and support they need.

Ruth Sutherland, Acting Chief Executive

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**Contributors**

**Caroline Bradley**
Freelance science writer Caroline Bradley has been keeping readers informed about dementia research for the last six years. Originally a radio journalist, Caroline has worked for several national charities and is currently working with local community organisations to improve their communications. She is passionate about removing barriers to understanding. She lives in Yorkshire.

**Caroline Graty**
Caroline worked at Alzheimer’s Society until 2006, when she left to complete an MA course and embark on a new career as a freelance writer. As well as being a regular contributor to the magazine, she writes for a number of not-for-profit and public sector organisations, with a particular focus on health and the arts. Caroline lives and works in London.

**Dr David Lowery**
Dr Lowery is a researcher interested in older adult mental health. His interest in this area is both professional – he is currently manager of the EVIDEM research programme (see p15) – and personal, having helped a loved one live with dementia. David is currently working on a research project to investigate if regular walking can alleviate some of the symptoms of dementia.
By the time you receive this magazine, Dementia Awareness Week will be well underway, and will already have taken place in Northern Ireland. Let’s hope the Remember the person theme really does encourage people to take a closer look at dementia, and take the time to make friends with people living with the condition.

As Leslie Nottingham says on page 9, she doesn’t want the word dementia to frighten people away. She wants people to know her for who she really is – a sociable person who loves dancing and gets a kick out of bargain hunting in charity shops. What a great person to spend time with! As indeed are both John Wright and Phillip Joseph, who feature on pages 9 and 10.

Just a reminder, too, that there are still a few days left for entries for our Remember the person photography competition. The closing date is 10 July – see page 24 for details.

Rachael Doeg, Editor
**Volunteer vacancy**

The Society is seeking candidates for its investment committee, a sub committee of the main Board of Trustees. We are looking for candidates who have specialist knowledge of investment markets and working with fund managers. In particular, we are looking for people who can challenge our fund managers to ensure they are complying with our investment policy and strategy.

The successful candidate would also be expected to contribute to the Society’s investment strategy. It is anticipated that they will have worked at a senior level in a financial or investment organisation. Applicants will be expected to attend four meetings a year. The closing date for applications is Friday, 23 July. For an informal discussion about the role and details of the application process, please contact Matthew Sellen on 020 7423 3506 or email officer@alzheimers.org.uk

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**They made it!**

A team of victorious cyclists from KPMG completed the final leg of a 1,500-mile relay in aid of Alzheimer’s Society on 9 June when they crossed the finishing line in London’s Canary Wharf.

More than 250 employees and their families, plus alumni, clients and Alzheimer’s Society staff all rose to the challenge, joining the throng of determined cyclists at various points across the UK during the course.

The Big Blue Bike Ride, as the challenge was named, was formed of two routes which both led to Canary Wharf, one starting in Aberdeen on 28 May, and the other in Plymouth on 3 June.

As the team made it to the finishing line, they were greeted by ITN newsreader Nina Hossain and colleagues from the professional services provider, KPMG. Nina presented each cyclist with a medal and congratulated the team for helping to raise around £100,000 across the UK for Alzheimer’s Society, the company’s charity of the year.

ITN newsreader Nina Hossain greets elated cyclists at the finishing line
In brief

Be part of Memory Walk 2010

Memory Walk 2010 is the Society’s biggest annual fundraiser and is only two months away! Memory Walks are fun, family days out in many beautiful and interesting locations, and are a great opportunity to raise money and help fight dementia.

Memory Walks are being held throughout September across England, Wales and Northern Ireland. All the money you raise will be used to support services for people with dementia in your local area.

To find out more about your local Memory Walk, sign up online and get your sponsorship pack, please visit memorywalk.org.uk or call 0870 417 0192.

AGM materials

Inside this issue, you will find an annual conference programme and booking form for the Society’s annual conference, held between 17 and 18 September at the University of Warwick.

The conference encompasses our Annual General Meeting (AGM), which takes place on Friday 17 September at 6.30pm. The agenda, information and voting papers for the AGM will be sent to you with your August magazine.

Familial Alzheimer’s disease support group meeting

The Dementia Research Centre at University College London’s Institute of Neurology is holding a meeting on 30 July for people affected by Familial Alzheimer’s Disease (FAD).

The meeting aims to provide information about diagnosis and genetics, research into FAD, and to discuss the possibility of establishing a support group for people affected by the condition.

The meeting will be held on Friday, 30 July between 10am and 4pm at Wilkins Old Refectory, University College London, Gower Street, London WC1E 6BT.

For further information or to register, please contact Natalie Ryan on 020 7691 2303 (ext 723856) or email ryan@drc.ion.ucl.ac.uk. The closing date for registration is 22 July.

There is no fee for attendance, but registration is required.

New CEO

Jeremy Hughes, Chief Executive of Breakthrough Breast Cancer, has been appointed as the new Chief Executive of Alzheimer’s Society. Jeremy, who has been at his current charity for five years, is also Chair of National Voices, the umbrella body for more than 200 health and social care charities.

Alastair Balls, Chair of Alzheimer’s Society, said, ‘This is a critical time for the Society as we implement government sponsored dementia strategies. Jeremy will provide the insight, leadership, campaigning skills, commitment and energy to drive this forward successfully.’

Jeremy takes up the role in November.
In the press

The press team has been hard at work keeping dementia in the news and responding to journalists’ requests. Here are some of the stories you may have spotted in June. By Claire Bennett

Abdominal fat in middle age linked to dementia
Research by the Boston University School of Medicine published in Annals of Neurology found an association between fat levels and total brain volume. Lower total brain volume is a strong predictor of incident dementia.

Responding to the findings, Head of Research Dr Susanne Sorensen said, ‘We have all heard how a beer belly can be bad for our heart but this study suggests carrying excess abdominal weight could also increase your risk of getting dementia.

‘This is not really surprising as a large stomach is associated with high blood pressure, cholesterol and diabetes – all major risk factors for dementia. This large and robust study builds on the growing literature looking at links between obesity and dementia, but more work is needed.’

Bert Williams made MBE
Former Wolverhampton Wanderers footballer and England’s oldest surviving World Cup player Bert Williams was honoured for his services to charity and football in the Queen’s Birthday Honours. Williams, 90, was appointed MBE for services spanning seven decades, and described the award as the ‘icing on the cake’. Bert raised more than £100,000 for Alzheimer’s Society after his wife died with the condition. The story appeared in the Daily Telegraph, Daily Express and The Times.

Supplement in the Daily Telegraph

The Daily Telegraph produced a supplement entirely devoted to dementia on 27 June. To coincide with this year’s Remember the person theme, it featured author Terry Pratchett OBE discussing his experience of living with dementia. There were also interviews with Society ambassadors Angela Rippon and Tony Robinson, and Director of Research Clive Ballard, who emphasised the importance of increasing research funding.

Safeguarding scheme plans reviewed
Early reports suggested the government is to halt plans to roll out the Independent Safeguarding scheme (ISS) until a comprehensive review has been carried out. The scheme is designed to protect children or vulnerable adults, and was due to be introduced in July.

Commenting in the Guardian, our Director of External Affairs Andrew Ketteringham said, ‘People with dementia are some of the most vulnerable members of society. It is therefore essential that effective systems are in place to ensure they are not at risk of neglect and abuse. Any review must not scale back the scheme and make it any less robust. It has to cover people with different needs.’
I’m thinking about moving my mum into a care home. She has dementia and lives on her own, and I’m worried that she’s no longer able to look after herself so think a move may be for the best. My sister disagrees, however, so I’m not sure what to do. Can you help?

We get a lot of callers asking when the time is right to move people with dementia into care. Often, people have already made up their mind when they call, but just need some reassurance. The decision can be much more difficult when there are disagreements in the family about what to do for the best. Many people feel guilty when they start thinking about moving their partner or relative into a home, and this is understandable.

However, you need to consider whether moving your mum into care is in her best interests. There are a few things you can do that may help you make the right decision.

You could discuss the situation with someone from social services. They can carry out an assessment to determine your mum’s care needs, which may help clarify the type of care and support your mum needs, and the kind of environment in which it may be best for her to receive this care.

Some people choose to ask their GP for advice, as they may be able to discuss the situation with your mum and talk through the type of care she needs.

If your mum receives domiciliary care, her current carers might also have some thoughts on her care needs. Talking to other family members about the situation may be worth doing, too, so the decision doesn’t just rest with you.

A further source of information could be the manager of the care home you are considering moving your mum to. You could ask for an outline of the type of care your mum would receive there and to be shown around the facilities.

Once you have this information, it may be worth considering the benefits of a move to a home, or ways in which your mum could receive more care in her own home, if this option is possible. The main consideration in making this decision is to do what you believe is in your mum’s best interests. Speaking to other people first may help you and your sister decide what to do for the best.

By Sam Cox, Alzheimer’s Society National Dementia Helpline Adviser

The following free publications may help:

Community care assessment (418)

Selecting a Care Home (476)

Putting care right (838)

To order, call Xcalibre on 01628 529249, or download them from alzheimers.org.uk

To read more Q&As from our National Dementia Helpline, visit alzheimers.org.uk/helplinefaqs
Remember the person

By the time you read this, Dementia Awareness Week will be well underway. This year’s theme is Remember the person. Here, John, Phillip and Leslie, who are helping to promote our message, talk about:

**John Wright**

John is 68 and has Alzheimer’s disease. He lives in Tower Hamlets, where he enjoys being involved in the community and doing what he does best – entertaining people.

John says, ‘All my life I’ve been an entertainer. I had my own show as a female impersonator and toured the world with it. Danny La Rue came onto the stage and suddenly, drag shows were acceptable. Every pub was screaming for acts and we jumped on the bandwagon.

‘I miss that life very, very much but I run a pensioners afternoon on Fridays now and I look forward to it every single week. We do bingo, karaoke and dancing, and I’m happy because I’ve got the microphone in my hand again. Karaoke is the ideal thing for me because the machine tells me the words.

‘It was the worst day of my life when I found out I had Alzheimer’s. But I thoroughly enjoy helping to run the estate where I live and I hope that keeps me alert. I refuse to lie down, sit back and let Alzheimer’s take over me. Shoot me if you see that happening.’
Remember the person

By the time you read this, Dementia Awareness Week will be well underway. This year’s theme is Remember the person.
Here, John, Phillip and Leslie, who are helping to promote our message, talk about embracing life with dementia

**Phillip Joseph**
Phillip is 80 and lives alone with dementia, also in Tower Hamlets. A lifelong sportsman and spectator, he was a pole-vaulting champion of Grenada in the West Indies, where he grew up.

Phillip, also a tailor, says, ‘We grew up near the recreation ground in Grenada. I was there probably 365 days a year doing cricket, football and athletics. I was the best pole vaulter in my country. I used to pole vault with bamboo, which was quite dangerous as it could have broken.

‘I like to socialise a lot. Every year we go to a Grenada anniversary and meet people we haven’t seen from the early days. We remember what we did when we were back home in the Caribbean.

‘I have an open door to people I know. People come by and have a drink or two, and we watch sports on TV. It’s rare I don’t have someone with me.

‘I deal with dementia my own way. I live on my own and try to deal with it in the best way I possibly can. I take it in my stride.’

**Leslie Nottingham**
Leslie is 65, lives in Essex and has Alzheimer’s disease. She is a fun-loving person who thrives in company, and wants to be known for who she is, not for having dementia.

Leslie misses her job working in childcare, where she worked with families and ran clubs in nurseries. She says, ‘Some of the children had awful lives and the one thing I could give them was love and care. I really liked my job.

‘I still run a club once a week for adults with learning difficulties with a friend, which is similar to the other job but I don’t get paid for it!

‘I love clothes, dancing and being with people. I’ll dance to anything. If the music’s on, I’m on the floor. I hate being on my own. In fact if I’m left on my own too long it’s as if someone has taken the plug out. If I’m doing something or I’ve got something planned, I seem to live more, so I try to do something every day.

‘I’m very lucky in lots of ways. I’ve got some really lovely friends and my daughters are brilliant. I’m still a person. I don’t like the word dementia, because you can see the look in people’s eyes, as if I’m going to turn into some strange person. And I’m not! My worst thing is that I don’t remember anything.’

To watch John, Philip and Leslie talk more about their experiences of dementia in short films, visit alzheimers.org.uk/remembertheperson
Without the support of our dedicated fundraisers, the Society simply couldn’t achieve its goal of improving lives for people with dementia and their carers.

Sarah-Jane Szikora is a Gateshead-based artist best known for her colourful, quirky paintings of ‘fat ladies’ and gingerbread characters. Here, she talks about her mother’s dementia, why she is supporting the Society through her work, and humour in her art.

Sarah-Jane Szikora’s mother was diagnosed with Alzheimer’s disease five years ago. She says, ‘We lost my dad ten years ago. Mum lived on her own for five years, and around the time she was diagnosed she met someone else who’s now her main carer. Steve’s in his 70s and he drew the short straw really.

‘It’s so unfair on him as he came into her life and I feel is burdened with her care. He lives with her and cares for her 24/7. I moved in with mum for six months a year ago to help care for her on a daily basis, and it makes you realise just how difficult the condition is.

‘Steve has also had a stroke, which I believe was triggered by having to cope with this. He doesn’t like asking for help. I try to help out where I can, but I’m working full time and more, and there’s all the guilt associated with mum’s illness.

‘I’ve tried to organise respite for them but it’s not working terribly well as the woman who comes isn’t trained in dementia care. We’ve avoided using services we haven’t needed at certain stages, but the situation is changing now and we’ve been in touch with the Society locally.

‘I don’t think it should fall to charities to provide care and support for people, but it does.

Thank God for Alzheimer’s Society. I thought I may be able to help in the course of what I do.’

Sarah-Jane kindly donated a print which was auctioned for £3,000 at a fundraising event for the Society, and most recently created two limited edition designs for our 2010 Christmas card collection.

Speaking about her work, she says, ‘I mostly draw my ideas from simply observing people and human behaviour. There’s a lot of depressing art out there. Artists will respond to social difficulties and I do the same, but there’s still humour in them.

‘I love the challenge of finding humour in an ordinary situation. Life has so much misery and tragedy, I like to search out the good bits and make people laugh. If I’m struggling with a blank canvas, I take myself off to a local town centre. Often I need only see a mundane scene such as the purchase of a bag of chips and I am on my way.’

Sarah-Jane recently spent a week working with the senior nursing team at Bradford teaching hospitals as part of a King’s Fund project called Enhancing the healing environment, aimed at improving the dementia wards. We will be writing more about the project in a future issue.
In the February issue of Living with Dementia, we set out some of the pledges the main political parties had made in response to the issues facing people with dementia and their families. Now, two months after the formation of a new Conservative-Liberal Democrat coalition government, the political landscape has changed – and it is vital we all take action to keep dementia on the agenda.

**Manifesto pledges and government commitments**

For the first time in an election campaign, all three main political parties made specific commitments to dementia in their manifestos. This was a terrific achievement, and testament to the hard work of Alzheimer’s Society staff, volunteers and campaigners who helped put dementia at the top of the agenda.

The coalition has published a programme for government, a document that sets out its vision for the next five years. Within this plan, it has made a number of promises that will affect people with dementia – including a commitment to set up a commission on long-term care that will look at a range of funding options. The programme also includes a commitment to prioritise dementia research funding.

Alzheimer’s Society welcomes these commitments, but we need to ensure the new government delivers on its promises and recognises that people with dementia and their carers need a better deal. In the current financial climate, it is more important than ever to step up our campaigning efforts to ensure dementia is a top priority.

**What next?**

Alzheimer’s Society’s public affairs team has already written to all MPs briefing them about the key issues affecting people with dementia and their families, and urging them to support our work. The team is also inviting MPs to join the All-Party Parliamentary Group on Dementia, a group of MPs and Peers which raises awareness of dementia among parliamentarians and seeks to influence legislation and policy-making on the condition.

**How you can help**

We know that MPs are more likely to prioritise issues when they are raised directly by their constituents, so it is vital your MP understands your experiences and the difficulties you face, and what needs to change. This election saw 232 new MPs elected to parliament, many of whom may have little knowledge of dementia or its impact in their constituency. Whether you have a new MP or not, please take the time to contact them explaining the difficulties you face, whether it be funding for care, access to services, or the quality of care in your area.

For more information about the new government and Alzheimer’s Society’s campaigning priorities, or to sign up to our campaigners’ network, please log onto www.alzheimers.org.uk/campaign or email campaignersnetwork@alzheimers.org.uk
To Spain and back

Peter and Ann Oldacre took early retirement to settle in southern Spain, where they were looking forward to a stress-free life in the sun. Their plans fell apart, however, when Ann started showing signs of dementia. Here, Peter tells their story.

We were living in a flat in Bristol where Ann was working as a travel agent and I was working for a manufacturing company. I’d been ill for some time, so we decided to retire early.

We didn’t know where to go. We have children and thought that as Spain is only two hours away on a plane, we could get back easily if we needed to. We were going to buy a villa with a pool and live the good life.

We’d never been to Spain before, so we took time off work to go and have a look around different areas. It was like a fantastic long holiday.

We explored up and down the coastline, lazed in the sun and swam in the sea. We fell in love with an apartment in a place called Majaca in Andalucia. It had two bedrooms and was on a small complex just 200 yards from the sea. It was absolutely beautiful.

We started looking in January 2002, and by June of that year, we’d moved. I had a naval pension which was adequate to live on, and we had some money from our flat in Bristol.

We lived quite happily there and got to know people. I started doing odd jobs and we were going along nicely and nothing really happened until October 2006 when I started to notice changes in Ann.

She lost her enthusiasm to sit in the sun and go for walks. We used to do the crossword together but she couldn’t concentrate, her speech was becoming slow and she gained weight. Then there were two little accidents in the car when she forgot which way to go on the roundabout.

We came back to the UK to see the GP, who said Ann was depressed. Her mum had Alzheimer’s so we’d seen similar things happening to her. On one occasion, Ann had got lost at the airport and after that I found it difficult to leave her to
On one of our visits to the GP in the UK, Ann’s MMSE score showed she’d deteriorated incredibly quickly. The health service is brilliant in Spain, but unless you’re good with the language and can understand what’s happening, it’s very difficult. Their service also depends very much on families being involved and helping. I couldn’t work or go out and do anything. In the end, we had no option but to come back.

Back home
Ann’s very close to her sister, Sandra, so we moved in with her and her family in Monmouthshire. They had one son at home and their other son was at university. They gave us a big double bedroom and at this time Ann was still walking and talking, but she’d become incontinent and had collapsed a couple of times.

My naval pension was paying for our mortgage in Spain, but it was the only thing we had to live on. We were struggling. And staying with Sandra put a terrible strain on her and the family. At this time we still hadn’t had a diagnosis.

In the end, we saw a new consultant. I’d always had Alzheimer’s in the back of my mind, but it’s devastating when they tell you the news. Then it’s a case of, ‘Thank you very much, goodbye,’ and you walk out of the door, thinking ‘What the hell am I going to do now?’

Sandra mentioned Alzheimer’s Society, and I went to one of their evening meetings for carers. I was the youngest person there by 20 years or so. Ann had just had her 60th birthday. I was put in touch with a woman called Anne Carpenter, who supports younger people with dementia at the Society.

Without Anne, I don’t know what we would have done. Just filling all the forms in for benefits was a nightmare. You don’t know where to start. There are lots of black and white questions but the answers aren’t black and white.

Selling the house in Spain was also proving to be an absolute nightmare. I didn’t have Power of Attorney so we couldn’t sell it as it was in both our names. We had to do everything in front of

When Peter and Ann Oldacre sold up in England to move to Spain, they were looking forward to the good life in the sun.

They bought their dream apartment in Andalucia, and settled into what they hoped would be a long, happy retirement. When Ann’s behaviour started to change, and Peter felt he could no longer leave her alone, they decided to move back to the UK. Without the necessary language skills or family support, they had little option.

Now 62, Ann is doubly incontinent, immobile, and hasn’t spoken for the last two years. They live in a remote hamlet in Wales in a council owned bungalow, and Peter, 64, is taking medication for depression.

He said without the support of Alzheimer’s Society, he doesn’t know how they would have coped. He is grateful for the support he has received, but says, ‘This isn’t quite the life I had imagined. It’s difficult, it really is difficult.’
the notary over there, and everything had to be translated, which cost a fortune.

We were running up huge bills going backwards and forwards to Spain, and all we had to live on were Ann’s disability living allowance and her state pension. It took a year to sell the house. By this time, Sandra’s son was due back from university, so we had to get a letter from Sandy to say we were going to be made homeless so we could get a council house.

We moved to a bungalow in a hamlet called Cross Ash, between Abergavenny and Monmouth.

Life today
This place is on top of a mountain in Wales. It’s ten miles from the nearest shop, and there’s no public transport. It has a beautiful view but isn’t designed for someone who’s disabled. We had no idea how quickly the disease was going to affect Ann. When we moved here, she was still walking and talking. She soon started falling more, lost the ability to stand and walk, and hasn’t spoken to me in the last two years.

There was a period when everything was going wrong, and to get help from anyone was so difficult. People don’t tell you in advance that help is available. When Ann first became incontinent, I’d go to the chemist and spend all our money on incontinence pads. No one told me you could get them from the NHS or that an incontinence nurse could come and do an assessment.

Trying to get what you are entitled to is so difficult and so frustrating. There have been times when I could just walk down the road, get on a plane and fly back to Spain and let someone take over.

I get a break three days a week. Some days I go back to bed, and some days I shop as it gives me something to do. Alzheimer’s Society has opened up a memory café and carers meetings in Abergavenny and Monmouth, so I go every couple of months.

It isn’t quite the life I had imagined. I’m on the happy pill. I go to carers meetings and it’s good because they tell you it’s okay to be depressed and angry and frustrated, because if you bottle it up you won’t do yourself any good.

It is heartbreaking to see someone you’ve been married to for a long time, the person you love and who you’ve had children with, disappear as the person they were. Anne was a bubbly, I’ll give-anything-a-go type of person. Some days she’s still there. She’ll give me a cheeky little smile, grab hold of my hand and not let it go. Some days it seems she knows who I am, other days I really don’t know.

‘But she’s not the same person anymore. It’s difficult, it really is difficult.’

Anne is 62, and Peter is 64. Their daughter, Andrea, lives in Wiltshire, and son Gary lives in Cardiff. Peter has made a film to show the impact of Alzheimer’s disease on Ann’s life, and to remember the fun-loving person who embraced life at every opportunity. He also wants the film to raise awareness of Alzheimer’s Society. We will include more details about the film when it is available to view.
Exercise and dementia

Observing a patient with dementia in 1907, German neurologist Alois Alzheimer wrote, ‘One of the first disease symptoms was a strong feeling of jealousy towards her husband. She could not find her way about her home, dragged objects to and fro, hid herself, or sometimes thought that people were out to kill her.’

This landmark description describes a complex experience including difficulty with thinking and memory, and paranoia and agitation. The latter two can be described as examples of behavioural and psychological symptoms of dementia (BPSD).

These symptoms are difficult to recognise and address. For the person with dementia, BPSD may reflect challenges of communicating thoughts and feelings. For carers and relatives, the need to provide constant reassurance and repetition can cause frustration. As a result, safety and quality of life can become hard to maintain.

Understandably, when BPSD become unmanageable, a move into a care home may be inevitable. This is a pivotal moment, not least for the person moving into an unfamiliar place, but also for those of us who wish to do more for our loved ones.

When BPSD strikes at the core values our relationships are founded on, including trust and emotional warmth, the damage can be considerable.

Research reporting the proportion of people experiencing BPSD is limited and we aren’t certain of the exact figure. However, one group reported that two in three people with dementia living at home experience BPSD. Within care homes, this number is greater, between 70 and 90 per cent.

We are becoming increasingly aware of the limitations of medications for the treatment of BPSD, but the search for adequate alternatives has been relatively neglected. While exercise is already known to provide therapeutic value for clarity of thought, we are less clear on the usefulness for BPSD.

Early indications suggest 30 minutes exercise daily can help promote regular sleep, reduce agitation, prevent depression and reduce the need for certain drugs.

However, this research is limited and we need stronger evidence.

Our project – EVIDEM-E* – is examining whether regular walking can be used to treat BPSD and the impact this has on quality of life. People with dementia living in London (North Thames) are invited to take part. Participants will be visited at a time to suit them and in their own homes.

The aim of the project is to find out if regular walking could prove an effective way of reducing BPSD. If successful, exercise therapy could provide an inexpensive and readily available intervention that will help improve the lives of both people with dementia and their carers.

*EVIDEM-E is part of a wider research programme known as EVIDEM (Evidence-based Interventions in Dementia) funded by the National Institute for Health Research. You can visit www.evidem.org.uk for more information. To find out more about taking part in EVIDEM-E, or to receive updates about the research programme, please contact Arlinda on 020 3214 5886 or email acergapashoja@nhs.net.

For research references contact rdoeg@alzheimers.co.uk

Researchers in London are looking for participants for a project investigating the impact of exercise on alleviating particular symptoms of dementia. Senior Research Programme Manager Dr David Lowery explains more

alzheimers.org.uk
Explaining dementia to children

When a person has dementia it can affect the whole family, and young children can find it particularly upsetting. They can be distressed by changes in a relative’s behaviour, or even worry that they are somehow to blame for the illness.

Eileen Mitchell is the author of It’s me Grandma! It’s me!, a story about dementia aimed at seven to eleven year-olds. The book was originally published in 1991, and was republished by Alzheimer’s Society in May this year. It aims to help a new generation of families explain dementia to their children and talk about their fears and concerns.

The idea for the book came about while Eileen was working as a senior occupational therapist supporting older people with dementia. She was one of the founding members of the Society’s Bridport branch in Dorset and ran carer support groups for many years.

During this time, Eileen saw first-hand the impact of dementia on young children. She says, ‘Children didn’t understand why their grandparent was getting cross or confused, or repeating themselves all the time. Carers were always asking about literature for children, but at the time there was nothing available.’

The seed

In 1986 Eileen visited the United States, where she came across a storybook about dementia called Grandpa doesn’t know it’s me. She brought back some copies for carers, and when one carer commented that the book didn’t reflect the experience of families in England, the idea for her own story developed.

Eileen’s colleague, Claire Stapely, produced illustrations for the original edition, and in 1991 the local NHS trust funded an initial print of 1,000 copies. Such was the demand that the book was reprinted a second and third time, with copies sold to people as far afield as China.

The aims of the book

Eileen says, ‘For me, the book was one way of helping children understand what was going on, so they knew that their grandparent was behaving differently because they were poorly.’

Eileen also wanted the book to show the realities of dementia. ‘The story is based on real services, and shows the progression of dementia. It prepares the way, showing in a sensitive way that the illness will get worse.’

The book also illustrates how children can maintain a positive relationship with a relative with dementia, for example by carrying out day-to-day tasks together in a way that benefits both the child and their relative.

It also proved a useful resource in local schools. Eileen visited schools to do readings and exercises with groups of children to demystify dementia. Eileen says, ‘Children as young as five would ask pertinent questions such as, “Is there a pill to make you better?” They were able to really grasp the ideas in the story.”

The Society has republished a storybook that helps young children come to terms with a relative’s dementia

By Caroline Graty

Eileen Mitchell and her grandchildren
While the story was a result of Eileen’s professional experience, it has since proved useful within her own family. She recently read the book with two of her step-grandchildren after their great-grandmother developed memory problems. Eileen says, ‘It’s good to have something to help children understand what is happening.’

The Society’s new edition has an updated look, with new illustrations from Melvyn Evans. However, the story itself is unchanged, and still reflects the experience of families with dementia today.

Eileen says, ‘I’m thrilled that the book has been published again. I hope people will find it as appealing and helpful as they did when it first came out.’

About the book
It’s me Grandma! It’s me! focuses on a little girl called Vicky and her relationship with her Grandma. It follows Grandma’s journey through dementia, from initial memory lapses to her move into residential care.

The story sensitively handles scenarios that many families who have experienced dementia will recognise. Grandma begins to get confused about simple tasks, goes missing when she can’t find her way home and sometimes forgets Vicky’s name.

Using simple terms, the book explains the role of the health and care professionals that families can come into contact with when they have a relative with dementia, such as a GP, a community psychiatric nurse and an occupational therapist. It also talks about services such as day centres, respite care and residential care.

It’s me Grandma! It’s me! costs £4.95 and can be ordered by calling Xcalibre on 01628 529240.

Dementia and children or young people (515) is available online and has more information on talking to children about dementia. We also have a free booklet entitled Talking to children about your illness (1507), aimed at people with dementia. To order the booklet call Xcalibre on the number above.

A further resource for children is currently in production.
A carer from Northern Ireland has been presented with a mini-break by Society Charity of the Year partners easyJet and KPMG in recognition of her caring role.

Wilma McMurray, from Doagh, was delighted to receive a break for two in Edinburgh, with flights donated by easyJet, and KPMG providing a stay in the Caledonian Hilton Edinburgh, courtesy of Hilton Hotels.

Wilma’s husband Jim was diagnosed with Alzheimer’s disease and bowel cancer at the age of 56, and Wilma has been caring for him for 13 years. She says, ‘I love Jim and am always there for him, but caring can be very tiring so it will be lovely to go away for a little while.’

The presentation was one of five made to carers around the country in recognition of their commitment to their loved ones. The other recipients were Elaine Butlin from Lewes, Pat Clements from Whitchurch, Anne Powell from East Didsbury, and Becky Smith from Newcastle.

easyJet will be raising money this summer through onboard collections, asking customers to donate their foreign and British change until 5 September.

Meanwhile, KPMG is on target to raise £1 million through the hard work of its employees, who have been holding cake sales, climbing mountains and cycling cross-country to support the Society.

Celebrating 25 years

The Society in Bexley is celebrating 25 years of services in the borough.

The festivities began on 13 May with a programme of entertainment in Bexley’s shopping centre, when founder member of the original Bexley branch, Gillian Collins, welcomed visitors.

Passers by enjoyed songs performed by pupils from four local primary schools, as well as a Punch and Judy show and a balloon launch.

The celebrations will continue throughout the year with events including a silver themed summer party and a group sing-along event in September with the Society’s celebrity supporter, David Van Day.

Tracey Errington, Support Services Manager for the Society in Bexley and Bromley, says, ‘We are very proud to be celebrating 25 years of service to the local community and were delighted that so many people came out to support us.’
Sunbeams light up the South Lakes

Members of Annie Mawson’s Sunbeams Concert Troupe were the stars at a fundraising concert in Kendal organised by former carer Cliff Dawson.

Ninety-year-old Cliff arranged the concert with Annie, who is founder and Chief Executive of the Sunbeams Music Trust. Sunbeams is an award-winning charity that provides therapeutic music for children and adults with special needs.

More than 150 people attended and the concert raised a grand total of £2,000, to be divided between Sunbeams and the Society’s work in South Lakeland.

Cliff chose to support the Society because of the help and support he received while caring for his late wife, Rae, who had Alzheimer’s disease.

As well as being a fundraising event, the concert was a tribute to Rae, who died last year. Cliff says, ‘When Rae was diagnosed she said, “I’m not going to let it get me down, and I’m not going to make a secret of it.” She was a great inspiration to others.’

Mayor’s choice

The Society in Yeovil was delighted to receive a cheque for £7,228, the result of a busy year of fundraising activities for one of the Mayor of Yeovil’s charities of the year.

The Mayor, Councillor Wes Read, chose Alzheimer’s Society and Leukaemia Research to receive the proceeds from a host of events. These included quiz nights, a concert featuring local musicians, and a fundraising ball at which Society ambassador Lynda Bellingham was a special guest.

Jill Lock is co-ordinator for services in the area. Jill says, ‘It was a great privilege to be chosen as one of the Mayor’s charities. Not only will the funds help our work supporting people with dementia and carers in the area, but the publicity has really raised the profile of the Society’s services here.’

WE WANT YOUR STORIES

Have you got a story you would like to share? If so, we would like to hear from you. Please contact our freelance writer, Caroline Graty on 07984 911913 or email carolinegraty@mac.com
In May, leading researchers from King’s College London (KCL) came together for a stem cell research forum to discuss how research in this area was progressing. The event was hosted at KCL’s Biomedical Research Centre, a cutting edge stem cell research facility.

What’s new?
Among the developments reported at the forum was the exciting news that results from research using stem cells to repair damage in the brains of people who have had a stroke would be available in the next two years.

Similar experiments in animals have shown that although stem cells introduced into the brain do not survive especially well, there are still improvements in the brain and in the symptoms of stroke.

As the new stem cells are not surviving to repair damage themselves, it is possible that instead they produce growth factors which help to repair the existing cells. If this is what is happening, these results open up new directions for stem cell research and the possibilities of new treatments for dementia.

What are stem cells?
Most cells in our bodies have specific roles, but stem cells are different. They are basic cells that exist in many of the body’s tissues, including the brain, liver, skin and bone marrow. Stem cells can develop into more specialised cells when repairs are needed. They can renew themselves and travel to a point of damage to replace lost cells, acting as a built-in repair kit.

If we can understand the mechanisms that control and direct stem cells, we could use them to treat damaged tissues and other cells. Given their ability to grow into nerve cells, they have the potential for treating neurological conditions such as Alzheimer’s disease and other causes of dementia.

Progress in Parkinson’s
The pace of stem cell research has picked up in the last five years, but work is still at a relatively early stage. Most progress has been made in the treatment of Parkinson’s disease, mainly because the disease is caused by the loss of one type of brain cell in a small area of the brain, rather than the widespread damage to many different types of cells that underlies most causes of dementia.

Clinical trials of a stem cell therapy for Parkinson’s disease have shown promising results, and the approach appears to be safe and effective. However, the technology is still in its infancy and there is much we don’t understand about the way stem cells function.

Despite this, a number of centres in Germany and Holland, among other countries, are offering treatments for Parkinson’s and various neurological conditions including dementia, on a private basis. However, in the case of dementia, there is no evidence that these treatments are beneficial.
Stem cell research is a fast-moving area that seems to hold a good deal of promise for people with dementia.

The good news
Working out how to position and control stem cells in the brain is a difficult task. Not only would the cells need to be in the right place and respond to instructions to become the right type of cell, they would then have to integrate themselves into the brain and start functioning correctly. This is no small task, and treatments for dementia using this technique are most probably twenty years away.

However, the possibility that new stem cells could have a general but positive effect on the brain by producing growth factors offers hope, because it means the actual position of the stem cells is less important.

To date, it has been difficult to find ways of successfully introducing growth factors into the brain. Alzheimer’s Society’s Director of Research, Professor Clive Ballard, is extremely hopeful about this area of research. He says, ‘If we think outside the box a little, we could be looking at a new treatment for dementia in five to ten years.

‘Harnessing stem cells’ ability to produce growth factors could help to sustain nerve cells, enable some repairs and slow down the progress of the condition. The planned trials for people who have had a stroke are just around the corner.’

Even if the goal of a stem cell therapy is not realised, stem cells have more potential uses than a direct treatment for dementia. They can be used to tell us a huge amount about how cells in the brain function, thereby informing the development of treatment and determining the future path of research.

The Society is currently funding four projects that are exploring different ways of harnessing the properties of these industrious cells to help prevent and treat dementia.

Further reading
The current edition of Alzheimer’s Society’s research e-journal (issue 10) provides a comprehensive overview of key developments in stem cell research – visit alzheimers.org.uk/issue10

Research using animals has shown that while stem cells introduced into a damaged brain do not survive for very long, there is still an improvement in brain health. Researchers suspect this is because the stem cells produce nurturing chemicals known as growth factors.

Until now, the challenge has been positioning and controlling stem cells to repair damage in the brain. If stem cells can produce chemicals that lead to a general improvement in the brain, their location may not matter.
Hear, hear!
I would like to thank Barbara Pointon for her superb letter in the May issue about the withdrawal of NHS continuing care funding. She expresses the situation so eloquently.

My husband was diagnosed with dementia in 2003. I cared for him at home until February 2009 at which time, very sadly for me but out of necessity, he went into a specialist nursing home in Oxford where he has excellent care.

I know of five people with dementia whom, despite being in profound states of dementia, have had their funding withdrawn. The stress to carers is huge, and as Barbara Pointon points out, we suffer plenty of that anyway. I particularly agreed with her comment about people being ‘less trouble’ when they are cruelly rendered unable to do anything for themselves and how we as carers are increasingly unable to ‘entertain’ or help them emotionally or spiritually.

I am particularly aware of my husband’s lack of visuo-spatial and perceptual awareness. I don’t think he sees much at all that makes sense to him. This eliminates any pleasure gained from books or pictures and television.

Thank goodness for music and the human voice, and a recent aromatherapy and foot spa session organised by an inspired carer. Thank you so much for this letter and its publication, promulgating this problem.

Cecilia Adamson, Combe, Oxfordshire
‘...When it comes to pain relief in dementia, the inadequacies are well documented...’

Joyce Ruiz

Count me in!
I was shocked to learn from the letter from Barbara Pointon in the May issue of your magazine that many people are having their continuing healthcare funding withdrawn when they reach the severe stage of dementia.
Yes, count me in to join a campaign to stop this stupidity!

In addition to the points you raise, might I add the fact that even if you get the funding, it seems that you are unable to pay a top up out of your own pocket for the room of your choice at your existing care home.

It appears that the care home where my wife is has to re-tender for the care, and may well lose out to a cheaper/shared room at another care home with all the emotional upheaval that such a move entails. For this reason alone I have not even bothered to apply, even though my wife is at the severe stage as described by Barbara.

Contrast all this appalling nonsense with the NHS handling of a cancer patient and you see the bias of the NHS system against people with dementia. It is of course all about money, even though it does not comply with the basic principles enshrined in the NHS charter.

Michael Goldsmith, email

Review of Alzheimer’s drugs
I was very interested to read this news in your June magazine and agree that the advice given by the National Institute for Health and Clinical Excellence (NICE) regarding drug treatments for Alzheimer’s disease is very unhelpful. I feel my husband’s case history will support this.

Some two and a half years ago, we moved up to Yorkshire from the South West. For some time, I had noticed that my husband was becoming increasingly forgetful.

We went to the GP in March 2009 to ask about a memory clinic.

The GP referred us to a psychiatrist for the elderly and my husband was given a memory test by a community mental health nurse. His low MMSE score showed that he was ‘borderline Alzheimer’s’, and the psychiatrist prescribed Aricept, at first 5mg and then 10mg.

We had a further appointment in December, and in February this year went to a memory clinic. This time, his score was higher, the nurse finding that my husband was at the bottom range of normal. We have all noticed that he is much more alert and that his short-term memory, though not good, has improved.

I cannot say how grateful we are that we moved into an area where the health authority was prepared to go against the advice of NICE. Our very nice psychiatrist also believes that Aricept slows down the progression of the disease.

I do hope that you are able to influence NICE.

Penny Richards, Ilkley

Letter of the month
Congratulations to Joyce Ruiz for her letter, The dreaded assessment, our first letter of the month! The letter of the month was introduced in response to the popularity of the letters pages among readers.

Joyce will receive a bunch of flowers, courtesy of health supplement supplier Healthspan*, which raised £200,000 for the Society earlier this year.

Please just keep on sending your letters in as usual to the address below raising the issues that concern you, and sharing your views and experiences.

We very much look forward to hearing from you.

*Healthspan is the UK’s leading home shopping supplier of vitamins, minerals and health supplements.

We welcome your letters
Please write to Magazine Editor, Alzheimer’s Society, Devon House, 58 St Katharine’s Way, London E1W 1LB or email rdoeg@alzheimers.org.uk

Letters may be edited. We regret we are unable to forward letters on to correspondents without their prior consent. Letters for the August issue to arrive by 2 July. The views expressed in this magazine are personal and not necessarily those of Alzheimer’s Society. Editor: Rachael Doeg
Remember the person this
Dementia Awareness Week 2010™

This year for Dementia Awareness Week™, our theme is Remember the person. Throughout the week, we are encouraging people to look beyond dementia and understand that everyone living with dementia is still a person.

Our Remember the Person booklet, available from Xcalibre*, has ideas on how to befriend and support people living with dementia and their families.

As ever, we need your support to make the most of Dementia Awareness Week™. There is still time to enter our Remember the person photography competition – see alzheimers.org.uk/photocomp for details – but hurry! The closing date is 10 July.

Dementia Awareness Week™ runs from 4 – 10 July in England and Wales.

*To order the booklet, pictured above, call 01628 529240 and quote code 260.

Useful contacts

Alzheimer’s Society National Dementia Helpline
England and Wales 0845 3000 336
Open 8.30am – 6.30pm
Monday to Friday
Northern Ireland
028 9066 4100
Open 9.30am – 4.30pm
Monday to Friday

Alzheimer’s Society website
alzheimers.org.uk
Access all our factsheets
alzheimers.org.uk/factsheets

Living with Dementia programme
If you have dementia and would like to volunteer for the Society, call Jade Rolph on 07718 737 284 or email jrolph@alzheimers.org.uk

Alzheimer’s Society aims to publish clear, accurate and independent information for people with dementia and their families and carers. The Society is pleased to receive funding through sponsorship but does not endorse any products those sponsors produce.

Changing your details

If you need to update your address details or inform us of any other changes, please contact membership enquiries on 0845 306 0868 or email membership@alzheimers.org.uk

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