

Dementia in Scotland



Issue 89 – Spring 2016



**Get your
mind & body
active with
our new
campaign**

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Welcome to the spring edition of Dementia in Scotland.

It is with great pleasure and enthusiasm that I introduce our new fundraising and awareness campaign called 'Challenge Dementia'. Those of you plugged into social media or tuned into Capital Radio will already be aware of the campaign, which launched this spring. The campaign aims to raise money and promote dementia risk reduction messages by encouraging people to get their bodies and minds active with physical and mental challenges. As well as helping Alzheimer Scotland to fund projects and support for people living with dementia in Scotland, the campaign will also challenge discrimination, isolation and stigma that people living with dementia face, by sharing stories and talking openly and honestly about dementia. I've already pledged my own challenge to support the campaign and I hope you will join with us to make 'Challenge Dementia' Alzheimer Scotland's biggest and most successful campaign to date. Find out more on pages 4-5.

In this edition you will find an article that outlines our commitment to technology and innovation. We recently launched the first ever Technology Charter for people living with dementia in Scotland. It calls for the delivery of health and social care to people with dementia to incorporate and promote the use of technology, helping people with the condition to live healthier, safer, more active and more confident lives as valued citizens.

We have a special feature on people with dementia and stress. Dr Barbara Sharp, Policy and Research Advisor at the Alzheimer Scotland Centre for Dementia Policy and Practice at the

University of the West of Scotland, has completed a PhD study involving people with dementia as active research participants and has made a careful analysis of their accounts of experiencing stress. The results of her research are incredibly important and insightful. Find out more on pages 22-23.

Of course this May sees the Holyrood elections, which are a fantastic opportunity for us to speak to candidates throughout Scotland and make them aware of the important policy and practice changes needed to make Scotland a world-leader in supporting people with dementia. For those who wish to get involved in supporting our priorities, we have provided resources both here in this magazine and on our website to help make sure the voices of people with dementia and their families are recognised and supported by your local candidates. Anything you can do to help remind our candidates of the importance and absolute necessity of good dementia policy and first class delivery of dementia services is very much appreciated and will go a long way to ensuring that dementia remains a government and political priority. Find out more about our election asks on pages 18-19.

Finally I am really looking forward to our conference this year. The team have secured some excellent speakers from across the world and of course some of the best leaders in the field from here in Scotland. I hope you can join us. You can read more about the conference on page 14.

Henry Simmons
Chief Executive
Alzheimer Scotland



We need you to Challenge Dementia

This spring we launched our Challenge Dementia campaign and now we need you to help make it our biggest and most successful fundraising and awareness campaign.

Challenge Dementia is all about getting your mind and body active and there's everything from walking, abseiling and running to quiz nights and cooking to choose from.

So far the response has been fantastic! People across Scotland have been keen to take on a challenge to help us raise vital funds to support our services as well as raise awareness of dementia, which affects more than 90,000 people in Scotland.

But we need even more of you to sign up to support our ambitious plans to increase support across Scottish communities for everyone with a dementia diagnosis. Get together with your friends and colleagues and sign up to the campaign at challengedementiascotland.org or call 0131 243 1453. Watch our Challenge Dementia short film featuring Scottish

actress, Barbara Rafferty and Scottish sports broadcaster, Alison Walker, at challengedementiascotland.org.

Explaining her support for the campaign, Barbara said: "my mother has lived with dementia for the past 16 years, so I really want to help make a difference and help raise as much awareness about the illness and of the challenges faced everyday by families across Scotland. Stand with me to challenge dementia and set your challenge today and you could be running or baking your way to success."

Figures show around 76% of people living in Scotland know someone who has the illness themselves or cares for someone with dementia, yet the stigma

around the condition still exists. Help us make sure families around Scotland don't have to face dementia alone and sign up to a challenge today. Let's Challenge Dementia together!

More info

You can test your physical fitness with runs, cycles, swimming and abseils, or keep your brain active by holding quiz nights or cooking challenges with work colleagues. Sign up to the campaign at www.challengedementiascotland.org or call 0131 243 1453.



"Stand with me to challenge dementia and set your challenge today and you could be running or baking your way to success."

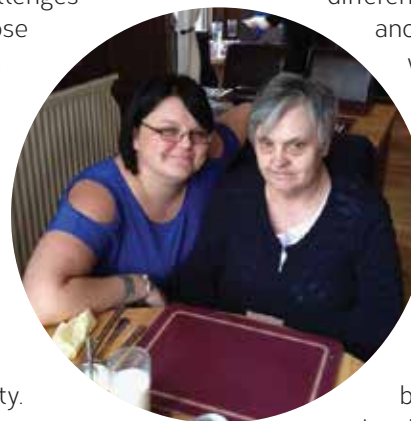
Meet the challengers!

Chris and the Run Beard Run team.

Chris McIntosh from Falkirk has teamed up with friends and colleagues to challenge themselves to multiple events during 2016 to help raise vital funds.

"This year I really wanted to challenge myself to support a good cause and decided on multiple events including climbing Ben Nevis. Together with a great group of like-minded friends, we are taking on challenges spread across the year and hope to raise up to £1,500.

"As a team we agreed to support Alzheimer Scotland. We wanted to help raise vital funds and increase awareness of the challenges faced everyday by those living with the illness. My fiancée works as a Senior Carer within a dementia care home and my grandfather has started to show early signs of dementia, so for me supporting the cause was a big priority. Anything we can do to support Alzheimer Scotland is time and effort well spent."



Amanda Levitt and her sister Sam

Amanda and Sam are raising money by staging a charity quiz and raffle in memory of their mum, Grace, who passed away with dementia aged just 64.

"Doing something to help people with dementia in Scotland is really important to me, not only because of my mum but because of the people I meet in my work too.

"I've raised money in the past, but this time I wanted to do something different and challenge myself another way. My sister Sam works in a local pub and suggested the idea of a quiz – they're always really popular in the town so it seemed like something we could do together. We've managed to source lots of prizes for the raffle and have been really overwhelmed by all the local support.

We've enjoyed planning it so much that we're considering making the quiz an annual thing in memory of mum and to raise money for people living with dementia at the same time."



Kevin Stump

Kevin Stump from Bo'ness is pulling on his trainers to take on a series of run events throughout 2016. The epic challenge will see

Kevin test his stamina and fitness as he prepares to run over 1000 miles.

"I work at The Flight Centre and was inspired by our charity partnership with Alzheimer Scotland. To challenge myself and dementia, I decided to sign up for a series of running events over the course of 2016 including the Great Edinburgh Run, Great North Run in Newcastle and the Scottish Half Marathon in May. My wife's grandparents have been touched by dementia so we have seen the effects a diagnosis can have on loved ones and the family. My bosses have agreed to match my target of £2,000, which would bring the total fundraising amount to £4,000 by the end of the year. With 129 miles under my belt, the year has kicked off to a great start!"

"As a team we agreed to support Alzheimer Scotland. We wanted to help raise vital funds and increase awareness of the challenges faced everyday by those living with the illness. Anything we can do to support Alzheimer Scotland is time and effort well spent."



Dementia Friendly Communities

Across Scotland businesses, service providers and cultural venues are recognising that dementia is everyone's business and there are benefits to be had all round when they make adjustments to become more dementia friendly.

Two organisations that have seen the benefits of becoming more dementia friendly are the National Galleries of Scotland and the Festival and King's Theatres Edinburgh. We spoke to Jeni Allison, Families and Communities Learning Coordinator at the National Galleries of Scotland and Paul Hudson, Forget Me Not Coordinator at Kings and Festival Theatres Edinburgh, about their work to be dementia inclusive arts venues.

What activities do you have for people with dementia?

Jeni: The National Galleries of Scotland runs Gallery Social, a monthly drop-in which includes a short gallery tour, a practical art activity and, most importantly, tea and cake! We also offer free tours, workshops and reminiscence sessions for care homes and day centres, just make sure to book four weeks in advance! .

Paul: We hold regular tea dances, lunches with live entertainment, plays and family friendly events. We also have monthly 'It's a funny old story' storytelling sessions, which we run in partnership with the Life Stories project. Stories are told, songs are sung and folk get to have a good old blether over tea, coffee and biscuits. In October, we will host the first dementia friendly performance of a major touring musical in Scotland when Chitty Chitty Bang Bang comes to the Festival Theatre.

How have you made these sessions dementia-friendly?

Jeni: Our artists and guides have worked extensively with people with dementia and understand the additional needs people may have. We offer wheelchairs, stools and hearing loops for anyone who might need them. We move slowly



around the gallery spaces and try to foster a relaxed atmosphere.

Paul: All our events are friendly and sociable in a relaxed informal setting. All of our staff are Dementia Friends. Our frontline staff have had, or will be receiving more in depth dementia awareness training too.

Why do you think it is important that people with dementia and their carers have these sorts of things available to them?

Jeni: A lot of people with dementia can become socially isolated; and having an engaging activity which they can take part in with a family member or carer can really help combat that. It's incredibly important to us that all audiences are able to access and enjoy our collections and exhibitions.

Paul: Sometimes when people are diagnosed with dementia they can stop attending the theatre or engaging in their usual social activities. Staff had noticed that some friends of the theatre suddenly stopped attending after many years. With our Life Changes

Trust funding, we've been able to set up a project to help people keep their connections to the theatre community.

How does being dementia friendly benefit your organisations?

Jeni: Being dementia friendly helps us to use our collections in new and innovative ways. It's really exciting to see a Van Gogh be used to spark a conversation rather than just being admired on a wall. Using our collection to engage with lots of different visitors allows us all to remember that art helps us connect with other people!

Paul: It has really helped us focus our already excellent customer service. It has also helped us examine how we can make our buildings accessible and friendly for everyone, not just people with dementia. Plus, with over 200 employees, we have members of staff who are carers and family members/ friends of people with dementia. The project has given them the confidence to ensure the person living with the diagnosis is able to live well and still engage with community activities and lead a full and connected life.

Is there a particular moment when you felt proud of your dementia friendly work?

Jeni: My proudest moment was when my granddad, who has dementia, came along to one of the sessions – a Robert Burns themed Gallery Social. After the session he recited some Burns poetry to me, and when I didn't know the next line he told me off. It was the most animated I'd seen him in a while!

Paul: There have been many moments, but the time our buildings consultation group were looking at the (lack of) signage in the Festival Theatre foyers springs to mind. I was explaining to one

of the group that we would be putting up more signs so it would be easier to find your way around. She looked at me as if I was a bit of an idiot and said 'so all you're doing is making things easier for everyone?' Which says it all really!

More info

Gallery Social: www.nationalgalleries.org/education/gallery-social-programme/
Forget Me Not project www.edtheatres.com/education/forget-me-not



Dementia Friends

This winter there has been no slow down in the number of people joining the ranks of our Dementia Friends initiative in Scotland. We're very quickly approaching the 20,000 milestone, with more requests from businesses, organisations and groups flying in every day. It seems everyone wants to know more about dementia so they can provide better service to their customers and their communities.

We have recently worked with staff from the Rangers Charity Foundation who are supporting us to raise £25,000 this year. We delivered two Dementia Friends sessions to Rangers Ticket Office staff and stewards. Bobby Merry, who works in the Ticket Centre, said, "I was really surprised by some of the things we found out, for example, that dementia isn't just about memory loss. The session changed how I think about people who are living with dementia and I can see it being useful in my work. Now I would feel much more confident speaking to someone I suspect might have dementia and making sure they receive the service they need."

Queen Margaret University has made a commitment to become a Dementia Friendly University. To support them in this aim, we'll deliver Dementia Friends sessions to all 1st year students studying nursing as a priority, with sessions also available to other students within the university.

Programme Manager, Anne McWhinnie, has also delivered successful sessions to the staff from Toshiba Medical Visualization Systems and Her

Majesty's Passport Office. These sessions generated a lot of discussion, questions and thoughtful moments.

More info

www.dementiafriendsscotland.org



Young people in Scotland care about dementia

When we speak to children and young people about dementia we're always surprised and heartened by how much they care about dementia, despite the fact it is often represented as an issue that only affects "old people". Across Scotland hundreds of young people are showing their support for people with dementia.

Over Christmas, pupils at Cullivoe Primary School in Shetland raised £350 for Alzheimer Scotland services. Primary 7 led the fundraising efforts, which included a project where pupils wrote special messages of support on Christmas bells instead of sending Christmas cards, and staging a special Christmas show.

Another important part of the project was learning about dementia. Claire Lawson, Headteacher at Cullivoe School commented: "We understand that when children feel informed they tend to cope much better. Every family knows someone affected by dementia and it is important children understand more about this condition.

"The pupils are delighted the money will be used to help local people and we will continue with learning more about the condition and its affect on individuals and their families."

In January, we launched an intergenerational project in Kilmarnock, which will see local schools working with us on a variety of activities, including work experience placements in our dementia café and helping out at allotments at Annanhill Walled Gardens. All of this is part of a wider drive to make Kilmarnock a dementia friendly town.

At the launch event, which was attended by Jim Todd Provost of East Ayrshire, pupils from Park School Primary were pleased to exhibit their photographs of landmark buildings around Kilmarnock. The aim of the photography project is to bring generations together through shared

history and heritage, and the photos will be used in our reminiscence sessions with people with dementia.

In Glasgow, Jordanhill School Charity Committee has been raising money for Alzheimer Scotland, with more events still to come. One of the highlights was the Halloween disco and its elaborate haunted tour, which was a great a success judging by the number of junior pupils quaking in their boots!

In addition, the "Jordanhill gives back" charity concert in November was a triumph, raising just over £2000. The raffle was a particular success, with many people commenting on the great prizes on offer.

Taylor and Ian from the Jordanhill Charity Committee commented: "Alzheimer Scotland is a cause important to many people in our year. The school community—pupils, parents, teachers and local businesses – have all been involved to raise as much money as possible for Alzheimer Scotland. We thank everyone who has helped this worthy cause."

We have also been delivering Dementia Friends sessions to Scout groups around the country. This is part of the Million Hands initiative which

aims to mobilise half a million Scouts across the UK in support of four social issues, including dementia.

In February, Dementia Advisor for East Renfrewshire, Richard Leckerman, delivered a Dementia Friends session to the 145th Glasgow Scout Group. Richard commented: "This was a really good session with a group of well informed children, willing to explore intergenerational opportunities."

Colin Lamont, Scout Leader, said: "The Scouts thoroughly enjoyed Richard's session and learned a lot about dementia. We're now looking forward to fundraising for Alzheimer Scotland to continue the positive impact we can make as part of our Million Hands initiative."



Dementia Ambassadors and Dementia Champions

This spring has seen over 200 professionals across Scotland graduate as Dementia Ambassadors and Dementia Champions.

On Friday 4 March 100 of Scotland's newest Dementia Ambassadors celebrated their graduation at a conference hosted by the Scottish Social Services Council (SSSC) at Dynamic Earth in Edinburgh. There are now almost 1000 Dementia Ambassadors right across Scotland in social service and other settings, whose role it is to promote best practice and support colleagues in their knowledge of working with people living with dementia.

A fortnight later, on 16 March, 97

health services professionals from all parts of the country graduated as members of Scotland's pioneering Dementia Champions Programme. The graduation event also recognised the success of 30 graduates from the Dementia Specialist Improvement Leads programme – designed specifically for mental health nurses working in specialist mental health services for people with dementia.

The graduates are the sixth cohort to complete the programme and bring the number of Dementia Champions in Scotland to around 600. Each Champion is dedicated to bringing about improvements in the experiences

and outcomes of care and treatment for people with dementia.

Improving the care and experience of people with dementia in acute general hospitals and specialist mental health dementia services are priority areas in Scotland's Dementia Strategy.

In a congratulatory message, the Cabinet Secretary for Health, Wellbeing and Sport, Shona Robison MSP, praised the graduates from both programmes on their completion and paid tribute to the time and effort they have put into the intensive training.

Participants for Cohort 7 are currently being recruited and will start their programme in May 2016.

Shifting the paradigm: new review

Shifting the paradigm together: Alzheimer Scotland Dementia Nurse Consultants and Allied Health Professional Consultants is a detailed review of the implementation of key healthcare commitments in Scotland's current dementia strategy – particularly the 10 care actions to improve hospital care – in 2014–15.

All of Alzheimer Scotland's Dementia Nurses Consultants and three AHP Consultants outline their experiences within Scotland's Health Boards; the changes they have made, the practice they have influenced and the role that Dementia Champions have often played in helping to improve acute healthcare delivery for people with dementia. Their work is underpinned by a four-strong national support team at Alzheimer Scotland. The review also outlines their role in sustaining the long-term impact of the Alzheimer Dementia Nurse and AHP Consultants and how, in partnership with the Scottish Government, plans are being made to extend these improvements beyond hospitals and into other aspects of healthcare for people with dementia in Scotland.



More info

"Shifting the paradigm together" is available to read online at www.alzscot.org/paradigm



Creating dementia friendly spaces on Scotland's high streets

Back in 2014 we opened the first of our new-look Dementia Resource Centres in Kilmarnock. Our aim was to create attractive, comfortable spaces for people with dementia, and also invited the general public in.

Dementia is the biggest health and social care challenge faced by society today. Figures show that 76% of people in Scotland know someone who has the illness or cares for someone who does. With this in mind, our aim is to put dementia firmly at the heart of our communities with Centres sitting alongside cafes, beauty salons and other local shops.

To do this, we knew we needed to create a modern, welcoming, high street presence that looked at home sitting between a Costa Coffee and the local green grocer. Working with users of the service, staff and award-winning design studio Graven, we have come up with a design template which we've been using and adapting with each new project.

The process ensures each centre has a local feel – while also being consistent with our other Centres across Scotland. This creates a sense of familiarity when visiting our Dementia Resource Centres and allows us to replicate good practice.

The challenges that people living with dementia have with their environments are similar to all of us, but exaggerated. Confusing and stressful environments are much more so for people living with dementia. There is a fine balance between stressful and stimulating environments, and that's true for people with or without dementia. Older people with dementia often have other physical challenges – like poor vision, impaired mobility, poor hearing – these factors have to be taken into account when designing our dementia friendly spaces.

People coming into our Centre will range from those who are living very well with dementia to those needing much more support – we need to ensure our design reflects these diverse needs.



Dementia friendly design in practice

On 22 January, we opened a brand new, larger, Dementia Resource Centre in Helensburgh.

Speaking at the opening of the new centre in Helensburgh, Sam Ross – a local person with dementia and longstanding supporter of Alzheimer Scotland's work in Helensburgh – welcomed the new premises, saying: "The extra space in this new Centre gives a great opportunity to expand on what is already provided. I really hope the people of Helensburgh come in to the café in the Centre; they'll see we're all Jock Tamson's Bairns. I've not looked back since getting involved with Alzheimer Scotland. Their support and advice has given me the confidence to get on with living my life."

The design of the Helensburgh

Centre follows our design principles, with lots of dementia friendly features.

Kitchen

We have used features like a glass kettle, which makes it easy for people to see how much water is in the kettle and whether the kettle is on. Open shelves help people find what they need easily, rather than opening lots of cupboards until they discover what they want and signs help people find quickly what they need.

Cafe

We have created a familiar and friendly environment where people can pop in for a cup of tea, a chat and some advice. They can also have a cuppa in a mug designed to be easier for people with dementia to hold.

Windows

The Centre uses glass room dividers to let light into the back of the building. However, plain glass can be confusing for some people with dementia so we have used attractive window designs which incorporate pictures of landmarks from around Helensburgh. These designs help create a visual boundary between two spaces and the local landmarks can be used as a talking point for reminiscence groups.

Communal space

In the communal space we've used attractive and contemporary furniture placed in small groups to make the space feel like a homely living room.

Products on Display

In a corner of the café we have an area which displays different products which can be useful for people with dementia. Each item has a short explanation of



how it can help. Each item was selected by Dementia Circle – an Alzheimer Scotland project which finds, tests

and shares everyday products to help people with dementia stay independent for longer in their own homes.

There are some basic formulas that help us make our centres good environments for people who have dementia:

- **Keep the layout simple** – open plan layouts with distinct areas can help people see where they need to go, while hallways with too many doors can be confusing.
- **Avoid complicated patterns and colour mixes** – this can be visually jarring and confusing.
- **Use appropriate sound, light, and contrast** – when used well, different sounds, colours and light combine to produce a stimulating environment.
- **Make the space homely** – use cushions and fabrics to make people feel more at home
- **Ensure social spaces are easily identifiable** – for example, making sure that the kitchen area looks like a kitchen with easily identifiable objects like a kettle, tea cups and a sink helps people to understand how to use that space.
- **Ensure signs are easy to see and understand** – signs should be at eye-level, with good contrast between the sign and the background, and directional signs can be used at points where people need to make a decision about where to go next.

Meet the 3%

Meeting in a small room in Glasgow, not far from the St Enoch Centre, is a diverse group of people. Their taste in music runs from Donny Osmond to Led Zepplin and The Cramps. Among them is a former school administrator, an offshore surveyor and a hairdresser. They've travelled from across the west to be here. So what has brought them together?

They all have dementia and they are all under 65. In Scotland, 3% of people diagnosed with dementia are under 65. For the past four months, Betty, Pat, Frani, Christine and Sharon have been meeting every Thursday morning at this Cognitive Stimulation Group. They share their experiences, enjoy therapeutic activities from arts and crafts to massage and singing, and – above all – have a laugh.

This group represents just five of more than 3,000 people in Scotland aged under 65 who have a dementia diagnosis. Dementia is not a normal part of ageing. It is caused by diseases which lead to changes to the structure and chemistry of the brain.

People under 65 with dementia can have a rather different experience of developing the illness to older people. Often they are still working and may have teenage children or students at university still dependent on the bank of mum and dad, they could be looking after their own elderly parents. It can also be more difficult to obtain a diagnosis as dementia will often not be top of the list when their GP investigates their symptoms. Younger people with dementia are commonly misdiagnosed with stress, depression or, in women, effects of the menopause.

For Christine, the time leading up to her diagnosis was incredibly upsetting and she is still troubled by the experience. "People I used to work with distanced themselves from me. There is a stigma and you don't understand that until you've lived with it. Last week I was out with a group of my daughter's friends from university. They all know about my dementia and they were so open and friendly. I really had a lovely time with them and that's how it should be. It gives me hope that younger people understand this better than my former colleagues."

Even once a younger person receives a dementia diagnosis it can be difficult



for them to access the support they need from the NHS.

Sharon, aged just 48 and the youngest in the group, explains "They don't know what to do with me! I'm too young for the dementia team so now they're thinking of putting me in with the mental health team. That's why this Alzheimer Scotland group is a great wee place to come. There's nothing else like it out there."

And she's right. Specialist services for younger people with dementia are few and far between, but it is important for younger people to have access to tailored support. A dementia diagnosis is life-changing at any age, but younger people can have different challenges in coming to terms with the diagnosis and may need special help to plan for their circumstances, like juggling finances to support children, sort out their mortgage and assistance to ask their employer for reasonable adjustments to be made to their job or negotiate an exit strategy if that's not possible. They also find greater benefit from being

part of a group where their companions are of a similar age, have overlapping interests and share cultural references.

This is exactly what Betty, Pat, Frani, Christine and Sharon get from the Alzheimer Scotland Younger Persons Support Service in Glasgow. The mood in the group is one of solidarity, warmth and good humour as they flick through the paper and chat about everything from politics and current affairs to celebrity gossip.

"We're a happy bunch, first and foremost" says Pat, a retired accountant. "We all have different types of dementia and we have different ways of dealing with it. But after coming here the main thing for me is that I know I can live with it."

The following week will be the last time the group meets because the 12 week block has come to an end. Susan Rendell, the Alzheimer Scotland Link Worker, who co-facilitates the group explains: "As the groups are time limited the endings are difficult for people, but we do keep in contact

Particular issues faced by younger people

In general, younger people with dementia are more likely to:

- be in work at the time of diagnosis
- have a partner who still works
- have dependent children
- have ageing parents who they need to care for
- be more physically fit and active
- have heavy financial commitments, such as a mortgage
- have a rarer form of dementia.

with everyone and do our best to arrange further support. We'll soon be welcoming a brand new group through our doors, and we'll begin to support people to reduce the sense of isolation and anxiety that can exist following a dementia diagnosis. These groups are essential, as there is very little out there for younger people that offers this kind of peer support. We hope the next dementia strategy will highlight the needs of younger people so that

resources can be expanded."

Lynne Meek, who facilitates the group alongside Susan, adds: "We recently saw the publication of recommendations of Dementia and Equality by the National Advisory Group on Dementia and Equality. This report has highlighted the need for increased awareness of younger onset dementia, clear pathways for referral and diagnosis and post-diagnostic support, as well as developing more services for younger people including respite services, care at home and long stay care. We very much hope that these recommendations are acted on so that younger people with dementia get the support they so desperately need and deserve."

This particular group is planning a goodbye party and everyone gets to choose a song for the playlist – what Betty, who loves Donny Osmond, will make of Sharon's selection of The Cramps is anyone's guess, but it's obvious that the solidarity between group members bridges the musical divide. They're already planning to get together over the summer when the group finishes. They'll be reunited by taking part in the Challenge Dementia

fundraising campaign to raise money for services like these, and they'll be entering the Memory Walk in September as a team: One Flew Over the Munchkins. Find out more about Challenge Dementia on pages 4-5.

"This Alzheimer Scotland group is a great wee place to come. There's nothing else like it out there."



Where to get support

Visit our website for more

information: www.alzscot.org/youngerpeople

Contact our freephone Dementia Helpline to find out what services are available near you

0808 808 3000 or email helpline@alzscot.org

Alzheimer Scotland Annual Conference – make sure you're a part of this great day!

Our Annual Conference is a real focal point of our Dementia Awareness Week activity. This year, it takes place on Friday 3 June at the Edinburgh International Conference Centre, and it explores the theme **Global to local: research, practice, innovation**.

The programme includes high-profile speakers from Scotland and around the world and hot topic parallel sessions, all in a world-class venue. There will also be plenty of opportunities to network with over 550 delegates in our biggest ever exhibition area.

Speaking about the conference, Amanda McCarren, a Care Manager said: "Alzheimer Scotland's Annual Conference provides me with the opportunity to meet so many different people who all share the common goal of wanting to help people with dementia and their carers."

Another former delegate Margaret Hence, who supports family member Derek who lives with dementia, added: "We love the Alzheimer Scotland conferences as they are so empowering for us both."

The conference is for everyone interested in or affected by dementia. If you care about making a difference to people with dementia, then come and join us.

Book now!

Secure your place at Scotland's leading dementia event. Early bird rate is available until Friday 15 April, bookings close Friday 13 May. Book online at www.alzscot.org/conference16 or call 0141 410 1072

£95 early bird members' rate available until 15 April. BOOK NOW!



Here are six highlights from this year's conference:

1. Living beyond dementia

Opening the conference is an inspirational and driven woman, Kate Swaffer, who is coming all the way from Australia to share her perspective on how to live beyond dementia. Kate was diagnosed with Semantic Dementia in 2008. Kate says: "I will share some of my learnings since diagnosis, and my theory of Prescribed Disengagement®. This is the term I use to describe the advice that health care professionals and service providers give to people with a dementia following diagnosis."

2. Dementia beyond drugs

Join Dr Al Power, an international educator on transformational models of care for older adults, at an enlightening breakout session: "Dementia beyond drugs". He will share some amazing insights into the use of psychoactive drugs at home, in care homes and hospitals, in the treatment of people with dementia in America and his passion to educate us to live beyond these drugs.

3. Research

We have three Ritchies discussing research! Dr Louise Ritchie will discuss a recent research project which explored the potential for people to continue working after a dementia diagnosis and what this could mean for employees and employers. Professor Craig Ritchie will discuss risk reduction and prevention and update on some of the incredible work being conducted here in Scotland. And Professor Karen Ritchie will discuss progress and challenges associated with pre-clinical dementia research.

4. Dementia Friendly Communities

Are you interested in how communities can change and adapt to become friendly and welcoming places for people with dementia? Come to our session on Dementia Friendly Communities for updates from around the world and explore what we can learn from them. Professor Huali Wang, of Peking University Institute of Mental Health, will provide insights into how China, the world's most populous nation, is turning to the community to help with challenges of mass migration from rural to urban environments and what that means for the ageing population left behind.

5. Debate

Take part in a lively debate on whether dementia should be diagnosed and treated by GPs or by secondary health care specialists like psychiatrists or neurologists. This is an important debate, and one that has been ongoing for years. It has far-reaching implications for funding and resources, and will impact on people's experience of being diagnosed and the treatment they receive.

6. Exhibition

Delegates will also have the opportunity to network in our largest ever dedicated exhibition space. With over 40 exhibitors to talk to, you're bound to discover something new and exciting in the exhibition hall. This year we have added "soapbox" sessions to the exhibition. These sessions give delegates the opportunity to hear about exciting and innovative products and ideas from a range of different exhibitors. The exhibitors will have 10 minutes, on a pop-up stage, to demonstrate their concepts and inventions and take questions from the audience. If you're not one of life's natural networkers, this is a great way to get the most out of the exhibition.

Carers cards

Supporting someone with dementia can put a lot of extra responsibility on to loved ones who care for them. Every day carers phone our helpline to get information and support, and they tell our helpline team about some of the challenging situations they have sometimes found themselves in. In response to hearing about these difficult moments, our helpline team has produced a 'carers card'. It's a very simple but effective idea – it's a discreet, credit card sized card that you can pass to people when you're out and about to let them know that you are a carer for someone with dementia. The card was designed and produced in consultation with the National Dementia Carers Action Network (NDCAN).

The card can be useful in a range of scenarios. For example, you may worry that if you're in an accident when you're out and about that nobody will know to make sure that the person you care for is okay.

"This handy sized card is ideal for carrying in your purse. An emergency can happen at any time and if for any reason you are unable to share the essential information, or due to emotional distress or panic forget

phone numbers, then phone and contact details are readily available" Maggie Muir (NDCAN Committee member)

"My mother is in a nursing home. Although I know she is well cared for there, possession of the card will allow people to know that if something happens to me, they must contact the nursing home to let them know" Thea Laurie (Friend of NDCAN)

You may also wish to use the card in day-to-day life as a discrete way of letting all sorts of people you come into contact with know that the person you are with has dementia and that you need a little bit of extra patience and understanding.

"This card has proven to be really useful when I take my mother out for appointments, for example to the bank, the optician or chiropodist, or even when meeting new people. It is a very discreet way of letting people know that my mother has dementia" (Friend of NDCAN).



More info

If you would like some cards to help you in your caring role, please get in touch with the Alzheimer Scotland Dementia Helpline on 0808 808 3000 or email helpline@alzscot.org. The Dementia Helpline is a free, confidential service which is available 24 hours a day, 7 days a week. You can find out more about NDCAN on the Alzheimer Scotland website: www.alzscot.org/ndcan

It's not always Alzheimer's

Alzheimer Scotland has created new materials to support people diagnosed with rarer types of dementia and those closest to them. The information sheets, collectively titled 'It's not always Alzheimer's', explore eight examples of less familiar forms of dementia including Frontotemporal dementia, Posterior Cortical Atrophy and Semantic Dementia. They will also be a useful learning resource for Alzheimer Scotland staff.

The catalyst for 'It's not always Alzheimer's' was NDCAN member Myra Lamont, who was determined to improve information on rarer dementias following the difficulties faced when her husband was seeking a diagnosis (he has Semantic Dementia). Myra worked with Jan Beattie (our Deputy Director of Workforce Development) and a group of Link Workers (Julia MacKenzie, Marian Garcia, Lindsay Voigt, Susan Rendell and Lynne Meek). They created a series of information sheets that reflected

the experiences of the people with rarer dementias receiving support from those Link Workers. Look out for a film in spring which complements the information sheets and features people with rarer dementias who are being supported by Alzheimer Scotland.

More info

The information sheets and short film for 'It's not always Alzheimer's' can be found on our website at www.alzscot.org/rarerdementias

New video helps people travel safely with dementia

This March, the Scottish Dementia Working Group (SDWG) launched an information video to help people with dementia travel safely and with confidence. The video is aimed at people with dementia, their families and carers.

The film was made by members of the SDWG, a national campaigning group, run by people with dementia and was funded by the Life Changes Trust. Vice-chair of the SDWG, Archie Noone, explained: "We want this video to help us travel safely with dementia wherever we are and whatever method of transport we're using."

The video gives tips on using a range of transport options, including in a car or taxi or by bus, train and aeroplane.

SDWG member, Nancy McAdam, said: "We want to travel safely with dementia. We have to be very careful when we're travelling because lots of accidents

happen when you're moving and we need to be aware of that, and be aware of the kind of things that can go wrong."

The video provides hints on adjustments you can make to your travelling environment to make it more comfortable and dementia-friendly. It also lets you know what services you might be able to access when travelling by public transport or at airports. Agnes Houston from the SDWG commented: "We use public transport a lot and I was finding it challenging because staff didn't understand. Because I wasn't physically disabled, staff didn't know how to assist me."

The SDWG hopes that by making this information available, people with dementia, their families and carers, will feel encouraged and supported to make full use of transport networks and maintain their independence.

More info

Watch the video at www.sdwg.org.uk/travelling



National Dementia Carers Action Network

Alzheimer Scotland's National Dementia Carers Action Network (NDCAN) held its annual open day in Glasgow on 23 January.

The day gives carers the opportunity to learn more about the work of NDCAN and how they can get involved.

Stuart Davids from Glasgow attended the open day, and commented: 'It was a very inspiring day. I'm extremely passionate about the care and treatment of people with dementia beyond the home setting. The experience I went through with my mum when she was admitted to a psychiatric unit was incredibly difficult, and I would love to be able to make that a million times better for people facing a similar situation in the future. I'm really looking forward to getting more involved with NDCAN in the future.'

The day also included presentations

from three guest speakers. Anna Buchanan, Director at Life Changes Trust, shared their plans to provide funding for more support for unpaid carers. Ruth McCabe, Policy & Engagement Manager, Alzheimer Scotland, spoke about the implications of the new Health and Social Care Integration programme for carers. Anne Buchanan, Nursing Development Manager at Alzheimer Scotland, examined how carers can become equal partners in care when the person they care for is living in an acute care setting.

As part of Alzheimer Scotland, NDCAN members play a crucial role in making sure the voices of carers are listened to, and that their experiences help inform policymakers, care staff and other professionals about the needs of those who care for people with dementia.

More info

For more information about the group and to get involved, visit www.alzscot.org/ndcan



Be part of Alzheimer Scotland's election 2016 Pledge on Dementia

On 5 May 2016 the people of Scotland will vote for 129 Members of the Scottish Parliament. Before that, Alzheimer Scotland is asking Scotland's election candidates to pledge their support for the 90,000 people in Scotland who are living with dementia.

As the number of people living with dementia in Scotland continues to rise, Alzheimer Scotland has set out a clear vision of the ongoing change required to properly support them, their families and carers.

People with dementia have the same human rights as every other person. These include the right to be fully included in their community and, when needed, to timely, skilled and well-co-ordinated, care, support and treatment, at home, in hospital or any other setting.

By ensuring that the rights of people living with dementia are fully recognised, throughout the illness, we can avoid the enormous human, social and financial costs of crisis-driven care.

We'll publicise the names of candidates who sign our pledge and will share your tweets, comments and shares on our website and social media, to encourage more candidates to support the pledge and to let our members, supporters and the 90,000 people living with dementia across Scotland know that you're backing them.



You can ask your local election candidate to support Alzheimer Scotland's Election Pledge on Dementia by:

1. Emailing them direct asking them to 'support Alzheimer Scotland's Election Pledge on Dementia'.
2. Tweeting them direct using **#AlzScot2016** asking them to 'support Alzheimer Scotland's Election Pledge on Dementia'.
3. Asking them in person if you attend a meeting or hustings, or if they canvass support by phone or in person.
4. Sending them one of the postcards included in this magazine. You can find their address details online or through your local council.

Thank you for making a difference

Get your election 2016 candidates to pledge!

This election, let's get your local candidates to pledge their support to people living with dementia in your area and across Scotland by making the following six commitments

“I support Alzheimer Scotland's vision of a Scotland that upholds the human rights of people living with dementia, recognising them as equal citizens, afforded dignity and respect and empowered to exercise choice and control in their lives.

To achieve this, I will work with colleagues in Government and new Health and Social Care Integrated Joint Boards to achieve the six goals listed here.”

These are all areas where MSPs can have an important impact as they carry out their roles in their communities and at Holyrood. You can quickly find out who your local candidates are and their contact details by entering your postcode at the website www.yournextmsp.com or contact your local council.



1. Help people who need one to get an earlier diagnosis

I will raise awareness of dementia, and encourage my local Integrated Joint Board to respond to the needs of people who have concerns about dementia so they feel supported and respected.

2. Make sure people with dementia and their carers get the support they need after a dementia diagnosis

I will urge my local Integrated Joint Board to put in place quality support for people after they have received a dementia diagnosis, so that they are able to live as independently as possible, for as long as possible, and to plan for the future.

3. Provide everyone with dementia and their carers with the integrated and coordinated care that they need

I will work with local Integrated Joint Boards to make sure that people with dementia can access the different types of care they need, and that these are arranged in a coordinated way that supports their individual quality of life, by a person who they know.

4. Support people with dementia and their carers through advanced stages of dementia and at the end of life

I will press the Integrated Joint Boards to recognise the value of continuity of care for people with dementia and make sure that the necessary expertise is available to the existing team to help them continue to support the person and their carer through advanced dementia and at the end of life.

5. To make sure that hospitals care for people with dementia properly

I will ensure the experiences and voices of people with dementia, their families and carers are heard by hospital leaders to drive improvements in care in hospitals

6. To encourage Scotland's ground breaking research into the care, cure and prevention of dementia

I will champion the globally significant contribution that research in Scotland makes to supporting people living with dementia today and in the future

Voting with dementia

On Thursday 5 May, Scotland will go to the polls to elect 129 members to the Scottish Parliament. People with dementia and carers often have questions about how to vote with dementia. Here we answer some of your frequently asked questions and provide some information on key things you need to know about the Scottish Parliament Elections.

The most important thing to remember is that a person has the right to vote and to make up their own mind about how they do that.



Can people with dementia vote?

The right to vote is a legally protected human right. People with dementia retain the right to vote, wherever they live, including if they are temporarily staying somewhere that isn't their usual residence. People retain their right to vote so long as they are able to clearly express their voting choice.

The decision as to whether and how to vote at an election must be made by the elector themselves, and not by a carer or a person making decisions on behalf of the elector.

Registering to vote

The rules about registering to vote have changed recently, and now everyone must register individually. You can do this online at www.gov.uk/register-to-vote or you can ask your local registration office to send you a paper form called an Individual Registration Form. All people wishing to vote must be registered by Monday 18 April.

Somebody else can help you to register by doing the typing if you are registering online or by filling in the form. You must tell them what information to use, though.

Ways of voting and how to get help

In person – by going to the polling station.

The polling station should be accessible and clearly signed, but the council officials staffing it will provide assistance about where to go and what to do.

A voter can ask for help to mark their ballot paper, either from the polling station presiding officer or from a companion: they should ask the staff at the polling station about this when they arrive.

By post – voting by post can help reduce the potential stresses of an unfamiliar environment like the polling station.

You can indicate that you want to vote by post when you register, and you will be sent the form, or you can get a form by downloading it from the internet or contacting your local electoral registration officer who can be contacted through your local council.

A signature is usually required on a postal vote, for security reasons, but if a voter is unable to sign their name or if their signature varies a lot, then they can ask for a waiver. If you want to do this, contact your local registration

officer and they will help you, usually by sending you a waiver request form.

Applications for postal votes must reach the Electoral Commission by Tuesday 19 April.

By proxy – this is when you appoint someone to vote on your behalf.

The proxy must carry out the intentions of the person on whose behalf they are voting.

You can get a form by downloading it from the internet or by contacting your local electoral registration officer. The form will ask you to provide the reason for requesting a proxy to vote on your behalf.

If you only want to appoint a proxy for a single election then you can give any reason why you will not be able to make it to the polling station – such as being on holiday.

If you wish to appoint someone to be your proxy for more than one election, a doctor, nurse or person in charge of your care home must sign the form to declare that you have a disability that will prevent you from getting to a polling station.

More info

Find out how to apply at

www.aboutmyvote.co.uk/register-to-vote/postal-vote-application

A guide to Alzheimer Scotland's development and innovation work

Joyce Gray heads up the development team at Alzheimer Scotland and she shares what her team has been working on.

I head up Alzheimer Scotland's development team. We're a small team but we are doing big work! We have the enviable task of investigating the cutting-edge approaches we can use here and now, and what our services should look like in the future.

We get to work in partnership with lots of exciting people – from large technology companies, to small start-ups, fellow charities and social enterprises. Wherever there is a good idea we're happy to work in partnership to see if it can be of use to people with dementia.

We work with people with dementia and their carers to see which ideas are truly useful and which ones end up being less viable once we check them out. Here, I have outlined a small selection of projects to give you a taste of what the Alzheimer Scotland development team is working on.

Dementia Circle

Dementia Circle is an Alzheimer Scotland funded project to find, test and share information about domestic products to help people with dementia.

From clocks and telephones to mobile apps, our team investigates, tests and recommends a range of products and services. All products are tested by people with dementia and are displayed in Alzheimer Scotland's Dementia Resource Centres (DRCs).

More info

For more information or to recommend products, visit www.dementiacircle.co.uk

Dementia Dogs

Our Dementia Dogs project has been one of our most popular endeavours yet. Interacting with pets has been shown to have great health benefits, both psychologically and physically.

This project has investigated the benefits of Dementia Assistance Dogs and smaller dog visits. Assistance Dogs live with a person with dementia and are trained to help with things such as remembering to take medication and sensing when they are distressed and calming them down. We also have other doggie days in our DRCs, and Therapets make visits to people at our day services.

We're working with University of West of Scotland and EKOS to evaluate these projects, but initial results show that Dementia Dogs have had a very positive impact on the lives of people with dementia and we're looking for funding to continue and expand the Dementia Dog project.

More info

Find out more at www.dementiadog.org

Dementia friendly environments

Our work around dementia friendly spaces covers a variety of different projects. One of the biggest areas we've worked on is the development of design principles for our DRCs, which aim to make our Centres inviting

spaces that people with dementia will feel comfortable in. You can read about the design of our DRCs in detail on pages 10–11.

We also work with housing associations and private care providers to look at residential care needs, including sheltered housing and full-time residential care. Looking to the future, it is interesting to think about what these services might look like for the baby boomer generation, who perhaps have a different outlook on life compared to the generation before them.

Technology Charter

In December 2015 we launched the first ever Technology Charter for people living with dementia in Scotland. The Technology Charter calls for providers of dementia services to consider how technology can help people with dementia to live healthier, safer, more active and more confident lives.

The Charter is a collaborative project, written in partnership with people living with dementia and different agencies in Scotland. It outlines the positive benefits of technology and how it can make a difference to people living with dementia and the professionals and family carers who support them. The Charter aims to drive change and to raise public and professional awareness of how technology can make a difference to the lives of those living with dementia.

More info

Download a copy of the charter at www.alzscot.org/charter. Or receive more information at tec@alzscot.org



Stress and coping – learning from the experiences of people with dementia

Dr Barbara Sharp, Policy and Research Advisor at Alzheimer Scotland, shares the story of her 25-year-long career at Alzheimer Scotland and reflects upon the findings of her recent research into stress and dementia.

For those who don't know me, my name is Barbara Sharp and I have worked for Alzheimer Scotland for 25 years – even as I say this I can't quite believe it! Over the years I've held several different posts in the organisation and I now work across Alzheimer Scotland and our Centre for Policy and Practice at University of West of Scotland (UWS).

I left school aged just 16 to earn my keep. I gained my first degree in my 40s, studying part time through the Open University. Six years ago I embarked upon part-time study for a PhD at UWS with support from Alzheimer Scotland. I now have a doctorate in nursing, having completed a research thesis entitled "stress as experienced by people with dementia: an interpretative phenomenological analysis." I'm still surprised at where I find myself now, but I was able to use the skills and knowledge I built up in my working life to inform my studies. I hope my experience can offer encouragement to those of you who may have left school at a young age too – it's never too late to pick up your education!

I was drawn to the subject of stress because it is a common experience in people with dementia, but one poorly recognised and understood. I felt this lack of understanding could be a barrier to people with dementia realising their full potential to live as well as possible with their illness. Furthermore, very little had been written about stress from the perspective of people with dementia themselves. I wanted my research to give a platform to people with dementia, so professionals like me could learn from their experience and understanding.

The study gathered experiences from people with dementia across Scotland through a series of focus groups. Those who participated in this study were

able to give their consent to take part. In these sessions we heard things that will ring true for many people but it is important to recognise that due to the individual nature of dementia these are not necessarily reflective of every person's experience.

The findings

Recognising changes in yourself and in the way others behave towards you was identified by participants as a major source of stress. Each day participants faced multiple reminders that their familiar life was under threat, which initially made it difficult to hold on to things that were important to their identity. They described the status of their relationships as being one of the most important signifier of loss or stability. Abilities that were lost – or inappropriately removed – compounded the sense that 'life is broken'.

'...that was my life and so that's what I want, I want to have that...'

Study participant Sandra

Some participants referred to 'grieving' for who they were, what life used to be, for relationships as they had been, and for a future which looked very different from the one they had anticipated. It is understandable that high levels of stress and feelings of grief may occur after a diagnosis. In people with dementia symptoms of stress were often read as solely relating to the physical illness, and therefore something that would not improve. The impact of high stress levels can present in a confusingly similar way to some of the more commonly experienced

symptoms of dementia – for example, difficulties in remembering, staying focused, making errors with everyday activities, getting upset, and feeling disconnected. The study found that stress can reduce as people gain more understanding of what is happening to them and begin to adapt and gain some control. Participants tell us that in time, and with the right kind of support, early stressful and threatening experiences can become familiar, and can be managed to some extent.

'...you start to become a prisoner of concern'

Study participant Ian

A significant issue for many of the people who contributed to the study was that they felt others, often those who mattered most, behaved in an overprotective manner towards them. This could lead to a sense of being 'monitored' and losing control over everyday decisions and activities. Participants expressed awareness of the stress experienced by their family members and that overprotective behaviour was most likely driven by best intentions. Nonetheless, it could reinforce unwelcome changes in their lives and make them feel less able than they believed themselves to be, further damaging already shaken self-esteem and hope for future improvement.

'It's been a hard, hard time...but they're not taking my hand – I've just got to get in there...'

Study participant Fred

Participants spoke of their frustration that professionals focused so much on memory loss when there were so many other features of their illness which they experienced and needed to understand. The lack of information about possible sensory changes, for example, had led to unnecessary uncertainty and distress. The stress of living with the functional difficulties that dementia brings, and the effort involved in adapting to doing things differently, means the whole experience can be quite exhausting. Speaking of the day to day impact of having dementia, overwhelming periods of tiredness was something shared by most and fluctuations in abilities were also common.

'...because the unknown fear of: "what's going on here? I mean, where did this come from?" ...'

Study participant Arlene

By its very nature, dementia presents us with a complex and dynamic situation: changes in the brain result in difficulties with a range of life's functions; how someone copes with these changes depends upon the kind of person they are, their life experiences, and the environment they inhabit. Furthermore our relationships shift and relationships are significant to the quality of our lives and the very sense of who we are.

In dementia, all involved can find themselves in a vastly changed personal landscape trying to do 'the right thing' but frequently having to operate with limited understanding of what that is.

A clear message from the study is the importance of working with the family and the wider networks of the person with dementia. It is possible to support people with dementia to

assimilate significant changes and explore new things which provide joy in life, but this requires the information and mechanisms for those affected by the illness to take control in their way and at a pace which provides space to mourn and adjust to changes.

'...the conclusion that I've been coming to of late is that one can help oneself...'

Study participant Anthony

All of this points to the importance of continuity in relationships beyond the intimacy of family to include available professional support so that understanding of what is a unique experience for each person is developed; trust is established to facilitate sensitive but essential conversations, and the flexibility to 'be there' when wanted and needed.

Across the board, study participants identified helpful support as something that was "strengthening" and I think we can all benefit from reflecting on this. I've pondered much on this and I'm not sure that even in all that I did to support my own mother I always came up to this mark. I don't suggest we beat ourselves up about what we haven't always got right but I do think we can learn from the mirror that people with dementia are able to hold up to us when we listen to their perspectives.

I think the overall findings of the study are hopeful in the potential shared by participants to recover a sense of self-esteem, value and purpose in life following a diagnosis of dementia. They also highlight the fragility of that potential and the responsibility of all of us to ensure it is realised.

Participants spoke of their frustration that professionals focused so much on memory loss when there were so many other features of their illness which they experienced and needed to understand



Barbara Sharp: PhD, BA Lit (Hons), PG Cert. Research Methods, RN (Adult), RN (Children), Lecturer/Practice Educator.

Relative values

Stewart Burrows from Dumbarton was diagnosed with dementia in September 2013, aged 59. We spoke to Stewart and Grace Wardrop, his partner of 32 years, about Barbara Sharp's research findings (pages 22-23) and whether their experience of coming to terms with dementia had similarities with the issues she identified.

Stewart

When I first read Barbara's research it really struck a chord with me. I did recognise a lot of it from my own experience.

One of the main things that jumped out to me was around the tendency for people to focus on the memory loss. I was in my late 50s and had just taken early retirement when I started noticing symptoms. For me, what I first noticed was my balance going. I had trouble getting out of my seat; I was staggering and weaving walking along the street. It wasn't until quite a bit later that I noticed my memory loss too. I was in the house all day when Grace was at work so I took on the household chores. I noticed I was getting very tired and having to take naps. I was also easily distracted. If the phone went I'd answer it and then forget I had dinner on

the hob. The amount of pots I ruined burning things! I'd give them a good scrub and hope Grace wouldn't notice!

Because I wasn't old, my first thought was that I maybe had a brain tumour. I was really scared, but finally I had a long talk with Grace about everything that was going on and decided to get myself along to the doctor. After a series of tests they diagnosed me with dementia. It was really heartbreaking but at the same time it was a relief that it wasn't a brain tumour.

After my diagnosis I didn't go out for about three or four months. I didn't want anyone to see me how I was. I suppose that was the grieving process Barbara talks about. I was grieving because I wasn't the person I had been. Things were changing. Luckily Alison Brady, the Alzheimer Scotland Link Worker got in touch with us. Between Alison and Grace they gave me a bit of a kick up the backside to get my life back on track. Alison got us signed up to a six-week course for couples, which talked us through the changes to expect and what we could do to cope with those changes. That course was so valuable. After that we knew what we were dealing with. Now I'm honest with Grace about what's going on and she's

honest with me too. We're able to adapt to whatever changes dementia brings.

My relationship with Grace has been very strong throughout and she really supports me. Actually since the diagnosis she's been less worried about me and protective of me because we know what we're dealing with. I did notice changes in my friendships though. A few so-called friends started to ignore me after the diagnosis. I had other friends who became overprotective. When they saw me out at the shops they would want to bundle me in the car and take me back home to Grace because they thought I shouldn't be out alone. There were people who would ask Grace about me while I was in the room, and I'd have to say "I'm here. Ask me how I'm doing!". That was all very frustrating at the time, they thought that because of the dementia I was suddenly not able to do anything myself. But that's all fine now. My true friends have learnt that I do still have my independence and a voice.

Our grandchildren Ross (10) and Amy (6) have grown up with my diagnosis and it doesn't phase them at all. If I get forgetful the just laugh and say "It's just papa's old timers." They just accept it as part of who I am.

One of my favourite experiences since my diagnosis was going to the Alzheimer International Conference in Slovenia last year. All of the lectures and workshops were tremendous. I had a wonderful time and met so many amazing people. The best bit was going to the ball and seeing all these people – people with dementia, their carers and people with a professional interest – everyone just dancing and laughing together. It was a great place to be.

Through Alzheimer Scotland I have become involved in the Pioneers, a group of people with dementia who go out to schools, hospitals and businesses and educate the public on the illness. I think it is so important that people know more about it and I am really proud of the work I do with the Pioneers. The best way to make life better for people



with dementia and their families is for everyone to understand more about it. That understanding helps to reduce stress and frustration and means everyone is able to cope better with a dementia diagnosis.

Grace

When we didn't know what was wrong with Stewart it really was a worry. I was still at work and I was really anxious about leaving him in the house alone. I'd call him all the time to make sure he'd had lunch or to check he'd turned the cooker off.

Having the diagnosis was a relief. Our approach was "this is what we've got and this is how we're going to deal with it." We realised that the dementia diagnosis meant we could still have lots of good years together. We were so relieved it wasn't a brain tumour.

Once we knew it was dementia we began to work around it and get used to

it. I could stop worrying about Stewart so much, instead we looked at how we could work around it. Some of it was really simple things, for example, we bought Stewart a bright red shopping bag. That way he knew if he was carrying the bag he was going out to the shops for something and it was nice and bright so it wasn't easy to leave on the bus by accident. We realised he was having trouble with his keys. When we counted them and found he had 19 keys on his keyring, for stuff he didn't need or know what it was for. No wonder he was having problems! We stripped it all back to just the ones he needed and colour coded them, which made life a lot easier.

Throughout all of this we look at the changes, whether they are physical changes or memory changes, we learn as much as we can, we talk about it a lot and together we decide how we're going to adapt.



Over the past three years we've learnt that laughter really is the best medicine. Sometimes you need a wee cry too, but we really don't dwell on the small things. The important thing is we're still enjoying life together.

Supported by

Alzheimer Scotland Annual Conference

Global to local: research, practice, innovation

Friday 3 June,

Edinburgh International Conference Centre

Join 550 delegates from home and abroad to discuss the latest hot topics. This is a conference for everyone – from people with dementia and their carers to academics and health and social care professionals.

To book go to www.alzscot.org/conference16 or call 0141 410 1072

See pages 14-15 for more information.

£95 early bird members' rate available until 15 April.

BOOK NOW!

Dust and Resin

A new short film from Edinburgh-born writer and director Stephen Parker explores issues of dementia, loss and loneliness. The film stars veteran Scottish actor David Hayman and new-comer Zoe Barker. The short film has been touring major international film festivals, including London and Toronto and has been met with critical acclaim.

Speaking to Zoe about her role in the film, she said: "My grandmother had dementia so it was a real privilege for me to take part in this film. The character I play has no knowledge of dementia, so I had to detach myself from my personal experience, but my understanding of the illness definitely helped."

Stephen explains why he wanted to explore the theme of dementia: "My grandfather passed away a few years ago with Alzheimer's. He wasn't fully aware of the changes in himself; the person who really struggled with the situation was my gran and I wanted to examine this."

"In the film I put together two very different people to see how their meeting could help explore the situation. I put them in a position that was misleading to challenge perceptions. I hope the film will challenge and entertain audiences."



More info

Dust and Resin will be available online later in the year. For updates and information go to www.dustandresinmovie.com

Books

What the hell happened to my brain?

Kate Swaffer was just 49 when she was diagnosed with a form of younger onset dementia. In this book, Kate describes vividly her experiences of living with dementia, exploring the effects of memory difficulties, loss of independence, leaving long-term employment, the impact on her teenage sons, and the enormous impact of the dementia diagnosis on her sense of self. Never shying away from difficult issues, she tackles stigma, inadequacies in care and support, and dementia myths perpetuated by the media, suggesting ways in which we can include and empower people with the diagnosis. You can hear more from Kate at our Annual Conference. Find out more on pages 14-15.



Please Don't Forget: A story of dementia

This photographic documentary by granddaughter and photographer Zaria Sleith captures the heart ache, the laughter and stories of her loving grandad who had dementia.

The book shows the reality of life with advancing dementia; there's the specialist paraphernalia and equipment encroaching in many of the images, but in every photo the warmth and spirit of Jimmy and his family shines through, reminding the viewer of the importance of our unique identities, relationships and love for each other.



Dear Mama

This February, Drumchapel singer-songwriter John Condron released the song Dear Mama. The song is dedicated to his mother Linda, who was diagnosed with dementia in 2010 aged just 54.

Dear Mama is a beautiful and touching song that will resonate with countless people who love and care for someone close to them with dementia. John is very kindly donating all profits from the song to Alzheimer Scotland.

More info

Find out more at www.alzscot.org/dearmama

"the song will resonate with countless people who love and care for someone close to them with dementia"



Learning a new language after a diagnosis

At the end of 2015 a new scheme was launched to support people with dementia to keep their brains active by learning a language. Lingo Flamingo is a social enterprise founded by Robbie Norval, who was inspired by his grandmother who had dementia, and by his experience working in care homes.

The project provides tailored lesson plans and interactive workshops. Participants can choose which language they want to learn, with the most popular languages being Italian, Spanish, French and German. A recent study has suggested a link between learning a second language and improved cognitive function, although specific research with people with dementia is yet to be carried out.

Sessions are delivered at a range of locations including in residential care homes, day services and in Alzheimer Scotland's Dementia Resource Centre in Kilmarnock.

Grace Sloan, Home Manager at Balhousie Wheatlands Care Home,

added: "Lingo Flamingo's foreign language workshops have proved very popular with many of our residents. It is fantastic to see how they respond to the activities and the enjoyment they get out of every session. Dementia can be a very isolating and frightening illness and we are delighted to be working with Lingo Flamingo to help residents use these inspiring techniques."

Mr Norval said: "A range of therapies to help tackle dementia currently exists but Lingo Flamingo is the first enterprise in the country to focus on foreign languages."

Some people have been surprised that we're teaching people with dementia a new skill, but we provide participants with ways to help remember vocabulary through memory and visualisation techniques, which can be useful beyond the classes.

"The sessions we deliver are fun and inclusive, so alongside the health benefits of keeping the brain active, they also help tackle feelings of

isolation by helping people to socialise with others who have similar interests."

More info

To find out more about Lingo Flamingo, visit www.lingoflamingo.org



Around the world

International conferences

Alzheimer's Disease International will hold their 31st International Conference in Budapest, Hungary from 21-24 April 2016. Research, care and policy issues will all be covered at the conference under the theme of "Dementia: Global Perspective – Local Solutions". Registration is open until 12 April. Tickets can be bought at www.alz.co.uk/ADI-conference

The 26th Alzheimer Europe Conference takes place from 31 October – 2 November 2016 in Copenhagen, and is hosted by Alzheimer Europe. The theme of the conference is "Excellence in dementia research and care". Early bird registration is available until 30 June. Book now at www.alzheimer-europe.org/Conferences

British Consulates in Spain seek to improve dementia support for expats

The British Consulates in Alicante and Malaga are working with local charities to improve services offered to people affected by dementia. This February, the Consulates hosted dementia learning events in Alicante, Murcia and Malaga. The events sought to help organisations understand the different types of dementia and offer ways to overcome barriers to communication with people affected by dementia. Both Consulates and local organisations see cases of elderly British residents with substantial care needs who have little or no resources or family to support them, and have urged British nationals to register with the Spanish authorities

to gain access to services. Find out more online at www.gov.uk/guidance/healthcare-in-spain

Dementia Dogs down under

In Melbourne, Nina the first ever Australian dementia dog, started work in October 2015. HammondCare, a specialist dementia charity in Australia, is behind the Dogs4Dementia programme which has had a wonderful response so far. Alzheimer Scotland's Dementia Dog project was happy to support this new project in Australia, passing on information about our service design and experiences. We are look forward to continuing to work in partnership and sharing our mutual learning.

Cottages and Castles provide a helping hand for families living with dementia

Our friends at Cottages and Castles have extended their kind offer of life-changing holiday breaks for people living with dementia for a further year. This partnership between Alzheimer Scotland and the Scottish holiday let company has delivered 16 self-catering breaks in luxury cottages across the country to date.

Cottages and Castles Manager Sue Bourne lost her mother to Alzheimer's Disease in 2015 so she understands how challenging day-to-day life can be caring for a loved one with dementia. Sue said: "Everyone deserves to get away and take time out somewhere peaceful so we worked hard along with our generous holiday home owners to make the project a reality."

Sheena and John McCall from Dalgety Bay are among the families who have already enjoyed a welcome break thanks to the generosity of Cottages and Castles. Sheena explained: "John was diagnosed with dementia

in 2007 aged 60. He was showing signs of forgetfulness for a while and eventually couldn't go out on his own. My daughter told us about the holiday project as she saw a flyer at the local hospital. We decided to go for it as it had been a good few years since we had the chance to get away and enjoy some time together. The holiday gave us the chance to stay 4 nights in a beautiful rural cottage in a lovely quiet location. John even brought his camera which he loved using until recently. On this holiday he picked it right back up enjoyed taking pictures of the local scenery. This holiday really gave him a big boost. We've always been so close so the break really gave us the chance to cherish the time we have together."

Planning a break with family members who have dementia can be challenging, but with some small adjustments, holidays can still be happy and memorable occasions.



More info

If you would like more information about how to apply for the next round of donated breaks from Cottages and Castles please contact Angi Inch at Alzheimer Scotland by email at ainch@alzscot.org

Creative Breaks

This year Alzheimer Scotland has allocated over £28,000 of funding in collaboration with Shared Care Scotland to help 100 carers and families living with dementia take a break from day-to-day challenges. Ivan Williams from Alva explains how he used his Creative Breaks grant to create a special space for his family.

My mum Nina is 94 and has been living in sheltered accommodation for 27 years now. She was diagnosed with dementia back in 2013. It has been a lot of responsibility looking after mum, and some days I can stop in up to three or four times a day to check she's okay.

Back in 2014 we went through a very difficult time when mum really wasn't well and in and out of hospital. As an only child, it was all taking its toll on the family and I felt I wasn't spending

enough time with my wife.

Early 2015 we took the big step of buying a static caravan and it's been the best decision we ever made. Setting up our new home from home was like starting off married life again. It felt wonderful! We are thrilled that the Creative Breaks grant has helped to make the caravan a special place for us. It's our little haven in Anstruther. We might only be away for a couple of days holiday but it feels like a week! Mum's been up for a day trip and she loves it too. I'm really happy that we invested the money in something that we can enjoy and share with our friends and family.



Short
breaks fund

Dementia Awareness Week Scotland 2016

Monday 30 May – Sunday 5 June



From **Memories Days to Cake Bakes, Tea & Blethers to Purple Parties** – there are so many ways you can show your support and raise money.

Get involved at www.alzscot.org/DAW2016



Thank you Scotmid Co-operative!

A vintage tea party at East Calder Dementia Café marked the half way point in Scotmid Co-operative's Charity of the Year partnership with Alzheimer Scotland and Alzheimer's Society, which has raised an incredible £132,000 for the charities so far.

Over the past six months, Scotmid Co-operative staff, customers and members from across the business have gone above and beyond to make a difference in our communities for people living with dementia and their families. From quiz nights and sponsored runs, to store raffles and head shaves, the engagement, commitment and support from staff and customers has been fantastic. Thanks to their incredible efforts and generosity, the partnership is well on its way to meeting the ambitious £250,000 target

by September 2016!

Catherine Vasu (26) from Mid Calder, who works in the local Scotmid Co-operative and also volunteers at the Alzheimer Scotland East Calder Dementia Café, said: "I heard that the dementia café was looking for volunteers so I put my name forward. We need to look after and respect our older generation, so I'm just doing what I can to help out. I enjoy helping out in the café and can see the difference it makes to people's lives. There are lots of chats and laughter and always a cup of tea on the go."

Funds raised from our Scotmid Co-operative partnership will help to support our specialist, award-winning Dementia Advisor programme which delivers personalised, one to one support and advice to people with dementia and their families throughout

their journey with the disease.

Scotmid Co-operative is committed to creating new dementia friendly communities to help create a positive shopping environment for customers with dementia and have signed up to take part in a Dementia Friends training programme over the year. With staff members up and down the country taking part in information sessions and visiting the Memory Bus to learn more about the initiative, the business is well on the way to achieving dementia friendly status.

Through these dedicated fundraising activities and awareness raising initiatives, the partnership will help to build a better, brighter future for people with dementia and their families.



Wheatley Group

After a hugely successful charity of the year partnership with Wheatley Group, staff at the organisation have decided to extend their partnership with Alzheimer Scotland for another year! We have been so amazed by the level of support from staff across Wheatley Group raising over £8,000 over the last year. Staff in Loretto Care have also been involved in the Dementia Friendly Glasgow strategy, as well as lots of housing support officers taking part in Dementia Friends. We can't thank Wheatley Group enough for their dedication to and enthusiasm for the work of Alzheimer Scotland this year. We are very much looking forward to continuing our vital work together throughout 2016.



Banking on a better future with HSBC in Scotland

Along with Alzheimer's Society, we have recently launched a new, UK wide, three year partnership with HSBC. Funds raised in Scotland will support some of our vital support services such as our National Freephone 24-hour Dementia Helpline and our Dementia Advisors.

Fundraising began with Tea & Talk events at HSBC branches over Christmas and will continue throughout the partnership.

Andy Maisey, Regional Director at HSBC, said, "Our Tea and Talks went

fantastically thanks to the support of our local communities. It was really valuable to spend the time with our customers, talking about why supporting Alzheimer Scotland and the Alzheimer's Society is so important to us."

HSBC staff have lots of fundraising and awareness-raising activity planned and staff are also giving up their time to help Alzheimer Scotland through volunteering with trips planned to our Bellahouston Allotment.

HSBC aim to improve the support

they offer to their staff and customers who might be affected by dementia and will be taking part in our Dementia Friends awareness-raising initiative. Alongside fundraising & Dementia Friends HSBC are also exploring how they can work towards becoming a dementia-friendly business.

We are looking forward to working with the team at HSBC over the next three years.

Award winning partnership with Sainsbury's Bank

Over the last 12 months Sainsbury's Bank have raised a fantastic £40,000 for Alzheimer Scotland from their office at Edinburgh Park. Their fundraising has been led by an immensely dedicated charity committee who organised a packed calendar of fundraising, including a Masquerade ball, Music Night, Christmas pantomime, bake sales, raffles, dress up days and participation in our sponsored challenge events!

Alongside a successful fundraising programme, Sainsbury's Bank also recognised the importance of educating

staff about dementia and how to better support customers living with the disease. Over 150 of their staff have become accredited Dementia Friends and they've held regular one-to-one sessions and dedicated dementia awareness events throughout the duration of the partnership.

We are delighted that our partnership with Sainsbury's Bank was recognised at the Edinburgh Chamber of Commerce Awards in February, where they received the Outstanding Corporate Social Responsibility award.



Celebrating our fabulous fundraisers

Here's a snapshot of some of the brilliant fundraising our supporters have been doing over the past few months.



This winter, members of Shall We Dance dance classes in Renfrewshire raised over £1,700 for Alzheimer Scotland. At one of the events, 100 guests turned out for a Bond themed charity dance evening, dressed as Bond characters. Thanks to everyone who took part!



Well done and thank you to everyone at ASCO in Aberdeen, where staff have been busy fundraising for us for the last year. Organising a range of events from clairvoyancy nights to bake sales, they have done an amazing job! This February they presented us with a cheque £20,015.



The wonderful Stepps Songsters held a music concert in aid of Alzheimer Scotland and raised a fabulous £565! They even invited our community fundraiser along to their rehearsals for a wee sing song – thanks Songsters!



This year the wonderful Men's Basketball team at Queen Margaret University are organising a number fundraisers for Alzheimer Scotland, including a "Take Me Out" themed event. They've raised over £500 so far. Thanks chaps!



Staff and family members from Camilla House care home in Auchtertool did a bungee jump raising over £1000. Thank you!



Family and friends got together to organise the 'Remember this 5k walk' in West Dunbartonshire after a beloved family member was diagnosed with dementia aged 57. They raised a fantastic £2,276!



Ann MacKenzie and her family held a Christmas fair in Carstairs Village Community Hall for Alzheimer Scotland and raised a whopping £1,350



Lodge St Andrew in Aberdeen raised £1000 at their Christmas carol service. Here they hand over the cheque to Andrea Watt, our new Community Fundraiser in the area.



Thanks to Janice Hendrie, who has raised a fantastic £885 for our Inverclyde services. She ran 8k cross country as part of the Scottish National Cross Country Championships at Callendar Park.

Dates for your diary

Whether you are interested in dancing the night away, taking part in a 5k run, listening to some excellent music, or attending a conference, there is an event coming up to suit you over the next few months. Visit our website www.alzscot.org for more information or call our Events Hotline on **0131 243 1453** if you would like to know more about any of our physical fundraising events.

May

Sat 14 May
Sun 15 May
28-29 May

Wigtownshire Sparkle Ball
Aberdeen Baker Hughes 10k
Edinburgh Marathon Festival

June

Sun 5 June
18-19 June
Sat 25 June

Great Women's 10k Glasgow
Edinburgh Night Ride [50 miles]
Tough Mudder, Drumlanrig
Castle, Thornhill
Forth Rail Bridge Abseil

July

Sat 23 July
Sun 24 July

Spartan Sprint Edinburgh [5k]
Spartan Beast Edinburgh [20k]

August

Sat 27 Aug
26-27 Aug
27-28 Aug

Dumfries It's A Knockout
Great Scottish Swim, Loch Lomond
Ride the North, [175k],
North of Scotland

Edinburgh Night Ride

Saturday 18 June – Sunday 19 June

50 miles, 1 night, see the city
in a new light!

Explore Edinburgh's
landmarks by night in
an iconic 50 mile cycle
challenge.

Find out more at www.alzscot.org/nightride or
call **0131 243 1453**



September

Memory Walks Scotland
Sun 11 Sept
Sun 11 Sept
Sun 11 Sept

Zipslide Across the Clyde
Great North Run, Newcastle
Pedal for Scotland, Glasgow
to Edinburgh
Scottish Half Marathon, Edinburgh
Loch Ness Marathon
Festival of Running

October

1-2 Oct
Sun 9 Oct
Sun 23 Oct

Great Scottish Run, Glasgow
Forth Rail Bridge Abseil
Survival of the Fittest, Edinburgh

Loch Ness Marathon Festival

Sunday 25 September

Soak up the scenery while taking
part in this Highland challenge!

From the full marathon to a 5k fun
run and the Wee Nessie for the kids,
there's something for every runner.

Find out more at www.alzscot.org/nessie
or call **0131 243 1453**

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Facebook: AlzheimerScotland
Twitter: @alzscot



Memory Walk Scotland 2016

Who will you walk for?

Put your best foot forward to help people living with
dementia in Scotland.

Find your nearest walk and register now at
www.memorywalksscotland.org



Let's **Challenge Dementia** together!



www.challengedementiascotland.org