Elaine challenges dementia with epic solo row in memory of mum
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Scottish adventurer Elaine Hopley makes history with solo Atlantic row in memory of her mum.

You can help us make sure that dementia is a top priority for every candidate standing in the local government elections. Find out how to get involved.

We take a look at the benefits of workplaces being inclusive and welcoming to customers and staff with dementia.

See inside our brand new Dementia Resource Centre in Stranraer.

Make sure you’re a part of the Alzheimer Scotland Annual Conference! We take a look at this year’s inspiring programme.
Welcome!

Spring is upon us and it brings with it new opportunities and new challenges for the team at Alzheimer Scotland.

This year the Scottish local elections are a huge opportunity for us to influence change in our communities. Many of the biggest decisions about funding for dementia health and social care services are made at council level. Our local staff will be working hard to make sure dementia is firmly on the radar with election candidates and will encourage them to sign up to our Dementia Pledge. On p.18 our Policy Team outlines this pledge and provides some ideas for making sure your concerns about dementia-related issues are listened to by your local candidates.

One key policy that is at risk of not being implemented fully because of decisions made at local level is the guarantee of one year’s post-diagnostic support (PDS). Funding decisions made by the Integrated Joint Boards, in localities across the country, are having a very real and tangible impact on whether people receive this lifeline of support from a Dementia Link Worker. Find out more on p.20.

This summer will again see us putting dementia in the spotlight with our Dementia Awareness Week activities. From Monday 29 May to Sunday 4 June Alzheimer Scotland staff, volunteers, partners and supporters will be flying the flag for dementia awareness, and I invite you to get involved. Host a Tea & Blether and invite your friends round to share a cup o’ kindness to raise much needed funds and find out more about dementia.

You can also join us at the Alzheimer Scotland Annual Conference on Friday 2 June to explore the big issues impacting the dementia community. It’s always an enjoyable and thought-provoking day and I really value this yearly opportunity to come together as a diverse group of people with a shared interest.

Finally, as we go to press with this edition of the magazine, the release of the next Scottish National Dementia Strategy is imminent. Our members, service users, staff and volunteers have been incredibly active in the consultation process and we’re hopeful that the new strategy will be an ambitious one that advances new initiatives as well as reinforcing existing policies. Stay tuned to our communications channels for an update on the launch.

2017 is shaping up to be an eventful and significant year and I am looking forward to working with you all to advance the dementia agenda in Scotland.

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Highlighting the gap between the post-diagnostic support guarantee and people’s experiences of service delivery.

In this edition’s Relative Values, meet Joan Porter and discover how she’s coping with the newfound fame of being a published author aged 85.

Meet the young volunteers who are making a huge difference at Alzheimer Scotland.
Elaine makes history in memory of her mum

A dventurer and Alzheimer Scotland supporter Elaine Hopley has rowed her way into the record books in a heroic solo row across the Atlantic Ocean. Elaine crossed the finish line in Antigua on 12 February after 59 days, 19 hours and 14 minutes at sea and she now holds the race record for the fastest female solo crossing. Elaine took on this mammoth challenge in memory of her mum, Jan, who passed away with dementia in February 2014. In a touching tribute to her mum, Elaine named her boat ‘The Jan’.

The race set off from the Canary Islands on 15 December 2016 and Elaine and her competitors had a gruelling journey of 3,000 nautical miles ahead of them, setting course for the finish line in Antigua. Throughout the challenge, Elaine kept supporters up to date with her progress on Facebook and Twitter playing games of ‘I spy’ with friends across the globe and recording sightings of wildlife including giant sharks, flying fish and stingy encounters with jellyfish.

While many of us were tucking into our Christmas dinner with family, Elaine was apart from her partner Ali and children Guy and Harvey, battling huge waves and wild winds in her 22-foot boat. Her Facebook update on 25 December read: “Merry Christmas everyone! Rowed through the biggest, scariest thunderstorm from 3pm yesterday until 4am, with exhausting high winds and torrential rain and me, white knuckle, hand steering ‘Jan’ (the boat). The sun is out now and drying out.”

Just before she completed her challenge, Elaine reminded her supporters why she was participating in such an exhausting journey: “For those of you who don’t know, my adorable Mum (Jan) had Alzheimer’s for 17 years which broke my heart. She fought it for so, so long just hoping there would be a miracle cure. She was the most beautiful, adorable mother even until the very end & this row is dedicated to her, for her courage & strength to keep going for so long. And so, my oars are back in the water for her & and also for all those who are going through the pain & suffering of Alzheimer’s – my heart goes out to you & your families.”

On arriving in Antigua, an elated Elaine said: “It was totally epic. It was unlike anything I could have ever imagined. There were some terrifying thunder storms where lightning bolts were incredibly close to the boat, but I pulled on through. It was definitely hard being away from my family over Christmas and New Year and seeing them all here today is just fantastic.”

The race organisers Atlantic Campaigns reported that Elaine burnt around 8,000 calories a day and lost approximately 20% of her body weight over the duration of the race. She endured sleep deprivation, sweltering heat and the psychological stresses of living and working in such an unpredictable environment, but she pulled through in true style. Duty Officer, Ian Couch, commented: “After a really tough time early on, frustrating conditions and a battle to make miles, Elaine has shown real grit and a great sense of humour.”

To date, Elaine’s row has raised more than £6,000 for Alzheimer Scotland and the total is still climbing. Elaine commented: “Thanks so much to everyone who sponsored me. It really
means a lot. I hope the money raised will go a little way towards helping to make life a bit better for people who have Alzheimer’s and for their families. I looked after my mum for over ten years, so I know just how much people need the support of Alzheimer Scotland, whether that’s through their support services or the research that they fund into dementia prevention.

Speaking about Elaine’s wonderful achievement, Alzheimer Scotland chief executive Henry Simmons said: “This challenge was absolutely incredible by anybody’s standards. Elaine is a remarkable athlete. Her strength and dedication, both in this solo row and in caring for her mum, show Elaine to be a true hero. We’re so grateful to Elaine for fundraising for us and to all those who were inspired to sponsor her. Your support means the world to us and the people we support.”

More info
If you’ve been wowed by Elaine’s amazing achievement, you can still sponsor her at https://www.justgiving.com/fundraising/Elaine-Hopley1
Stranraer Dementia Resource Centre

Last November, our brand new Dementia Resource Centre (DRC) in Stranraer opened its doors to the local community.

The Stranraer DRC is the latest of the new-look Alzheimer Scotland services to take its place in the heart of its community and bring dementia services to the high street in a bright and accessible building.

The new Centre is more spacious and better appointed than the previous premises, which means that it can offer a greater variety of services and more activities, including therapet sessions and hosting large-scale Dementia Friends sessions.

The hub of the Centre is the welcoming cafe where anyone from the local community can stop by and get information about dementia. Since opening, the cafe has attracted 10 new volunteers to the service and the new recruits are keen to increase their volunteering activity and to help with transport and day services too.

Service Manager, Clare Stroyan said: “It has been just brilliant relocating to this new, prominent site in Stranraer. Now everyone knows we’re here and the local community is keen to support us. We’ve been using lots of local services and suppliers for everything from the plants in our garden to the cakes in the cafe, which has been great for getting the local business community involved. Now they know we’re here if they ever need our help or if they want to fundraise for us.”

The Centre has also linked up with other charities to mutual benefit. A group of young men with barriers to employment have been volunteering at the Centre through the Apex Scotland U-Turn project.

Jackie Rae, Manager at the U-Turn project commented: “It was good to see the boys laughing and enjoying the company, and this is a mutually respected and valued partnership we have. The boys and I are looking forward to doing our Dementia Friends training, and feel we can put that knowledge to good use when helping people within our community.”

Linda, a local carer, said: “Knowing that the staff in the DRC are there makes me feel reassured, because coping with dementia can make me feel lonely.”

Local resident, Jim, commented: “The DRC is amazing and so good to see the building being used for a great purpose.”

The formal opening of the Stranraer DRC takes place on 24 March. Local MP Richard Arkless will lead the celebrations along with Finlay Carson MSP and Lord-Lieutenant John Ross.
Screen Memories Scotland

The power of film to connect people to their past makes it a valuable resource for reminiscence therapy. Over the past nine months, Michael White, from Alzheimer Scotland's sporting reminiscence projects, has been developing Screen Memories Scotland.

The project uses classic films and memorabilia to engage people with dementia in discussing and sharing their memories of the silver screen.

At a recent session in Helensburgh, the room was buzzing. “I remember him.” “They made me laugh.” “I couldn’t sleep that night after seeing that one.” “I used to have my hair just like that.” “I had a poster of her on my bedroom wall.” The pictures of the old film stars sparked great memories and the room was filled with laughter as people remembered the queues, the Saturday night sports papers, the usherettes, the Kia-Ora ice lollies and the ice creams.

An exciting new partnership with Regional Screen Scotland and other community film organisations is set to bring the Screen Memories Scotland experience to those living in remote and rural area communities.

More info

We’re looking to extend the pilot in 2017. Find out whether there are plans for a group near you by getting in touch. Contact Michael White 0141 616 6147 or email mwhite@alzscot.org

Facebook: Screen Memories Scotland
Twitter: @screenmemsco

Calling all carers!

Carers living in Scotland have been invited to take part in the Alzheimer Europe Carer Survey 2017.

People who are currently caring for someone with dementia in Scotland are being sought to participate in an Alzheimer Europe Carer Survey on the experience of diagnosis and post-diagnostic support.

The survey takes around 30 minutes to complete and seeks to gather information about carers’ experience of seeking help, the diagnosis of dementia and the support and help offered after a diagnosis has been made.

The survey will add to our understanding of the diagnostic and post-diagnostic experience from carers’ perspectives and help inform us where support and processes could be improved.

Professor Bob Woods from Bangor University has designed the questionnaire and will analyse the responses and produce a scientific paper with recommendations. The results of the survey will be published by Alzheimer Europe later in 2017.

More info

The survey will be available for completion from February until the end of April at www.alzscot.org/carersurvey2017

To request a paper copy of the survey please email publicpolicy@alzscot.org or call the Alzheimer Scotland Dementia Helpline on 0808 808 3000.
Tesco pilots ‘relaxed’ lanes

In January, a ‘relaxed’ lane was introduced at the Forres branch of Tesco. Checkout staff at the supermarket have been trained by Alzheimer Scotland to identify customers who might need a bit more time to complete their shopping and to operate at a speed that suits them.

Wendy Menzies, Dementia Advisor at Alzheimer Scotland, said: “We have supported the local Tesco team to help raise awareness of dementia and the steps they can take to help make a difference to the lives of people with the condition in the Forres area. “During our discussions with staff, we have looked at ways to create a dementia friendly environment on the shop floor.

“We welcome this new pilot scheme which will help people with dementia to feel confident in continuing to shop independently in their local community for longer. It should also benefit any customers who need that extra time without the stress of feeling they are holding up other shoppers.”

News of the pilot attracted worldwide attention, with media interest from as far afield as the USA and Canada. The story was also shared and commented on extensively on social media, with people from all walks of life taking to Facebook and Twitter to applaud the idea.

Tesco said it would wait to see how the scheme was received by customers before deciding on whether to expand it to other stores.

Alzheimer Scotland is continuing to work with supermarkets and other retailers across Scotland to raise awareness of dementia, particularly through our Dementia Friends programme. The relaxed checkout in Tesco Forres, the brainchild of the store’s community champion, shows that companies can make a huge difference by spending very little or no money – all it took was a good idea and some awareness training.

Dementia Friendly Glenrothes

Last September, Glenrothes was the latest town to add its name to the ever growing list of Dementia Friendly Communities in Scotland.

Alzheimer Scotland is working in partnership with Fife Council, Fife Health & Social Care Services and a number of other stakeholders to lead the initiative.

Louise Bell, Service Manager, Fife Health & Social Care partnership stated “It’s a real pleasure to be a part of this team which is aiming to inspire a dementia friendly approach in Glenrothes. We’re already working with local business owners and staff in our leisure facilities, shops, banks, parks, cinemas and restaurants to let them know about some simple and practical changes they can make to be more welcoming to their customers with dementia. The response has been incredibly positive.”

More info

Dementia Friendly Glenrothes is keen to make connections with local people living with dementia and with businesses, services and community groups in the area.

Get in touch with Amanda Hunter on 01592 803 800 or email ahunter@alzscot.org. Keep up to date on Facebook at www.facebook.com/DFGlenrothes
Dementia Friendly Prestwick

Since the launch of Dementia Friendly Prestwick in June 2016, much progress is being made to raise awareness and education around dementia and to include people with dementia, carers and families in community led activities.

It has been a busy first few months with lots of highlights, including the creation of a Dementia Friendly Community Garden at Biggart Hospital; a monthly pop-up sensory cinema, so far attended by over 200 local residents; engaging local schools in developing ideas to make Prestwick more Dementia Friendly; Lingo Flamingo Italian classes for local residents; Dementia Friends training for local businesses delivered by Alzheimer Scotland; and lots of charity events and fundraising including a ‘purple party’. Christmas cards and twiddle mitt sales and donations.

The Dementia Friendly Prestwick Team will update on their progress at the Alzheimer Scotland Annual Conference in June, where there will be opportunities to share information from dementia friendly communities around Scotland.

More info
Find out more:
Facebook: Dementia Friendly Prestwick
Twitter @dementiapwick
Web: dementiaprestwick.co.uk

Our new address

From 1 April 2017 our new address will be 160 Dundee Street, Edinburgh, EH11 1DQ.

We are sad to leave Drumsheugh Gardens but the Dundee Street office is much better suited to modern day working, it is more accessible for visitors and it will be more cost effective.

160 Dundee Street is a short 10 minute walk from Haymarket train station and is well served by public transport.

All staff telephone numbers and email addresses will remain the same, but please update our postal address to 160 Dundee Street, Edinburgh, EH11 1DQ.

Improving healthcare for people with dementia

Look out this summer for the publication of the Alzheimer Scotland Dementia Nurse Consultants’ and Allied Health Professional Consultants’ Annual Review 2016-17. The review will highlight the impact this group has had in improving standards of healthcare for people with dementia across Scotland by focusing on real-life examples from the 14 health boards, both in acute and community settings. It will also show the group’s influence in changing wider working practice within Scotland’s NHS. The review will be published during Dementia Awareness Week 2017.

Got a wedding coming up this summer?

We’ve got beautiful Alzheimer Scotland tartan accessories to lend a Scottish flavour to the happy occasion.

From beautiful shawls to keep the chill of your shoulders to dapper bow ties that will impress the other guests, you’re bound to find something to compliment your outfit. You can even buy the tartan by the metre if you want to have a full kilt made.

Shop now at www.alzscot.org/tartan
New year, new Chair and new priorities for the Scottish Dementia Working Group

The start of any year is always a busy time for the Scottish Dementia Working Group (SDWG), with a new committee and priorities to be set for campaigning in the year ahead. This year, though, sees particular changes in the group, with Henry Rankin standing down as Chair and Archie Noone stepping up to the job.

Henry has been Chair of the SDWG for the last four years, and describes it as ‘a great experience’ throughout which he has learned and achieved a lot. ‘People don’t realise that the Chair isn’t just a symbol, but that you actually have to work very hard’ says Henry, whose term has seen him travel internationally to speak at events, as well as participating in a number of campaigns and projects all alongside his chairing responsibilities.

Something he is especially proud of from his time as Chair is his commitment to fairness and ensuring that all members of the SDWG felt confident to voice their thoughts and get involved: ‘it was important to me that everyone in the group had a voice but that we could influence as a whole group rather than as lone voices shouting’.

During Henry’s time as Chair, the SDWG have ticked off a huge number of achievements: producing publications and films to raise awareness and fight stigma; playing a key role in the training of professionals; and building a strong relationship with MSPs and Government staff amongst many other successes. Henry is very proud of his achievements as Chair but looks forward to relaxing and spending more time with family in the coming years! He will stay on the SDWG committee and is confident that his successor Archie Noone will do a great job.

Archie was elected in a vote amongst Committee at the SDWG’s meeting in December. The SDWG Chair is also appointed Alzheimer Scotland Trustee and so Archie has been busy getting used to his new responsibilities since being elected.

‘I’m looking forward to getting a broad spectrum of people involved’ says Archie. ‘I hope we can open the group up even more and have lots of voices being heard’.

Archie notes that the role of Chair is different than being a general Committee member, and strives to be fair and patient, listening and taking it all in rather than always putting my own thoughts out.”

After some initial work planning for the year, the SDWG look set to focus on a number of issues in Archie’s first year as Chair, including ‘hidden disabilities’, local engagement and post-diagnostic support. Archie will be ably supported by two Vice-Chairs, Carol Hargreaves and Anne Macdonald, and a dedicated committee of 10. It looks to be another exciting year in SDWG history!
Happy Birthday to NDCAN!

In November, the National Dementia Carers Action Network (NDCAN) celebrated their fifth birthday. Carers Emma, Caroline and Bernard share some of their memories of the network over the years.

Emma: “For me, it started by writing a letter. I described caring for my mother as being like Alice falling down the rabbit hole, unable to stop or control the fall. A while later, an invitation came from Alzheimer Scotland asking me to help form a carers action group. There was a meeting in Glasgow for everyone interested. I was intrigued.

“That first meeting was attended by people of all ages with one thing in common – we all cared for someone living with dementia. The room was awash with emotion, as people shared their thoughts and experiences. There was anger, laughter, sadness and an overwhelming passion for change. It was electric.

“We were from all over Scotland – from Sutherland and Aberdeen to Perthshire, Fife and Glasgow. We heard about the issues impacting on carers across the country. We worked on the 8 Pillars Model of Community Support, supported campaigns for early diagnosis and gave talks all over Scotland. As word got out, people contacted us in increasing numbers to hear about our experiences as carers.”

Caroline: “While supporting both parents living with dementia, I often felt very isolated. When I joined NDCAN I found kindred spirits who not only understood what this felt like but also welcomed the opportunity of working together to improve the lives of carers of people with dementia in the future.

“Meeting the then Health Secretary, Nicola Sturgeon, set the path to raise the profile of carers of people with dementia.”

Bernard: “For me, NDCAN is where each individual voice combines to create one large, powerful voice. Working together like this we have more chance of making an impact and being heard. Being in the network has given me the opportunity to make a contribution. I hope that by sharing my experience of caring for mum I can help current and future carers in their dementia journey.

“An important thing about NDCAN is that we try to build on the positive aspects of what’s happening to create a better world for carers of people with dementia. I cared for mum alongside some wonderful professional carers and we need to showcase the good practice as well as drawing attention to problem areas.”

More info

Are you a carer of someone with dementia and want to make a difference? If you are interested in getting involved with NDCAN, please get in touch. You can visit the website at www.alzscot.org/NDCAN, email ndcan@alzscot.org, or call 0141 410 0100.
You’re invited to Alzheimer Scotland’s annual conference – the most important conference date in the diary for Scotland’s dementia community.

This year’s conference will explore big issues, from the impact of Brexit on research and collaboration, to challenging and trying to understand the often contradictory risk reduction headlines in the media about nutrition, food and drink. Plenary sessions will also ask pertinent questions of Government, the health and care sector, research and our own role, including ‘What’s next for Scotland?’ and query ‘Where is my new drug?’.

With such challenging questions on the main programme and the opportunity to pick from nine breakout sessions, which will cover topics from equality to caring by design, from the latest in technology and practice to innovation in day care, this is a conference you can’t afford to miss.

Book your tickets today: www.alzscot.org/conference2017. Early-bird rates are available until 7 April.

The presenters
This year’s programme will feature expert presenters from Scotland and the rest of the UK, plus international speakers from USA, Australia and the Czech Republic. Each will share their insights on the latest developments and innovations to help support people with dementia and their family members to live well with dementia.

Speaker highlights include:

› **Dr Martha Clare Morris**, an Associate Professor from Rush University in Chicago. Dr Morris is researching the MIND diet which is a hybrid of the Mediterranean and DASH diets. Martha will share with us her recent positive findings on adopting a MIND diet as part of a risk reduction lifestyle.

› **Peter Morgan-Jones**, an Executive Chef at HammondCare, will be inspiring us all with the creative ways in which food can be produced and presented for those in care homes or accessing day care services.

› **Helen Rochford Brennan**, Chairperson for the European Working Group for People with Dementia (EWGPWD), will be joining us to share why human rights play such a vital role in everyone’s diagnosis of dementia and treatment.

› **Dr Gary Stevenson**, a Consultant Psychiatrist in NHS Fife, will be exploring the challenges and hopes for the future design of services for younger people with dementia.

› Respected researchers based at Scottish institutions will present on their work, including **Prof. Craig Ritchie**, The University of Edinburgh. **Prof. John Starr**, The University of Edinburgh. **Prof. Debbie Tolson**, The University of the West of Scotland and **Dr. Karen Watchman**, University of Stirling.
5 reasons to come to the Alzheimer Scotland annual conference

1 Great choice
With nine parallel sessions on offer, delegates have the ultimate flexibility to tailor the conference programme in order to suit their specific interests. Parallel sessions will include:
- Connecting people, connecting support
- Caring by design – function vs aesthetics
- Nutrition, food and drink
- Make it equal – all of our roles in equalities and dementia
- Innovations in practice – music, film, dementia dogs and language
- Designing services for younger people with dementia
- Enabling technologies: technology and digital innovation
- Advanced illness, end of life and palliative care
- Capturing person centeredness – sex, diversity and hope

2 Diverse networks
The conference will see over 500 delegates come together under one roof to share their insights and experiences, and to discover new ways that we can all work together to improve the lives of people living with dementia. Delegates will include people with dementia, their carers, health and care professionals, as well as those with an academic, policy or business interest. These include the pharmaceutical industry and representatives from the finance, legal, property, technology and innovation sectors. The conference will be a wonderful melting pot of ideas and inspiration.

3 Big questions
Do you wonder what impact Brexit will have on dementia research and the Scottish research community? Are you frustrated with the lack of any new drugs? Can you make sense of the near daily newspaper headlines about dementia? Do you wonder what’s next for people living with dementia in Scotland? Join Alzheimer Scotland as we ask our speakers these vital questions.

4 Vibrant exhibition
From product demonstrations, to poster-board presentations, from show-and-tells, to videos – you name it, we will have it all in the exhibition area for 2017. Please view the website for a list of this year’s exhibitors. If you are interested in exhibiting, contact daw@alzscot.org for further details.

5 Real stories
Members from both the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) will be participating in key presentations throughout the day, providing unique insight into their opinions on the progress made to date, as well as hosting extended displays within the main exhibition area. Both groups encourage everyone to engage with them; to find out what the groups have on the horizon and to chat about how you could work with them in the future.

“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.” – Amanda McCarren, Care Manager
Food & drink: risk reduction and prevention

Will drinking champagne stop me getting dementia?

Mushrooms stave off dementia

Beetroot can fight dementia

Cut booze in middle age or risk dementia

A t this year’s annual conference we are putting the spotlight on nutrition, food and drink and in particular the relationship to risk reduction and prevention.

Every day we are confronted with media headlines and articles about what to eat and drink and what to avoid. These messages are often contradictory and give little or no context, making it difficult to make informed choices. So at our conference we’ve invited some key speakers to help us demystify some of these messages, to tell us more about their work in the fields of risk reduction and prevention and also to inspire us with insights and advice on mealtimes and menus.

Our speakers include:

- Dr Martha Clare Morris, Rush University Chicago, updating us on her research into the MIND and Mediterranean diet.
- Prof. Craig Ritchie, Director of the Centre for Dementia Prevention, The University of Edinburgh, looking at the bigger picture of nutrition, risk reduction and prevention.
- Prof. Colm Cunningham from The Dementia Centre in Sydney, on innovative approaches to food and drink particularly in dementia care settings.
- Executive Chef Peter Morgan Jones, from Sydney, looking at creative ways to keep food, drink and mealtimes both enjoyable and engaging.

The MIND diet

Join Dr Martha Clare Morris at Alzheimer Scotland’s Annual Conference to explore the MIND diet.

A study published by Dr Morris last year shows that the MIND diet lowered the risk of Alzheimer’s by as much as 53 percent in participants who adhered to the diet rigorously, and by about 35 percent in those who followed it moderately well.

The MIND diet is a hybrid of the Mediterranean and DASH (Dietary Approaches to Stop Hypertension) diets and has 15 dietary components, including 10 “brain-healthy food groups” and five unhealthy groups.

**Healthy**
1. Green leafy vegetables
2. Other vegetables
3. Nuts
4. Berries
5. Beans
6. Whole grains
7. Fish
8. Poultry
9. Olive oil
10. Wine

**Unhealthy**
1. Red meats
2. Butter and stick margarine
3. Cheese
4. Pastries and sweets
5. Fried or fast food

Come and hear Dr Morris speak about the MIND diet and pose your questions at this year’s Alzheimer Scotland annual conference! Book now at www.alzscot.org/conference2017
Celebrating art therapy

Exploring your creativity and expressing yourself through art and craft activities can be an incredibly positive and therapeutic experience for people living with dementia. Recently, works by people who use our services were featured at two inspirational art exhibitions.

In December, members of Alzheimer Scotland’s Solas Day Centre in the Western Isles had their work displayed at local arts hub, An Lanntair, as part of an exhibition showcasing the results of an island-wide quilting project. People with dementia were invited to get involved as part of the Arora Dementia Friendly Communities Project.

Quilting sessions were led by local artist and quilter Chris Hammacott who worked one-to-one with participants to create their own, unique quilt. This therapeutic activity was welcomed as a really positive experience by those involved. People were able to express themselves and communicate safely to tell their life story and create some wonderful pieces of unique and beautiful work. Tony Allan, who had his work featured in the exhibition, commented: “The quilt is going on the wall in my bedroom so I can see it last thing at night and first thing in the morning. My family all admire it and we have been talking about the images that were included.”

Ann Hill, Alzheimer Scotland Quilter in residence said: “What a great project! I have been encouraging quilters to get involved for several years. This is a huge success.”

Meanwhile, in Glasgow, users of our new Glasgow Dementia Resource Centre were taking a digital approach to their art.

The ‘What's Happening Now?’ project explored what impact creative activities using iPads might have for people living with dementia. This joint project between Luminate and Alzheimer Scotland was funded by Digital Scotland. The initiative tested the accessibility of different apps, and explored what things need to be taken into account when using digital media creatively.

Glasgow artists Janie Nicoll and Douglas Morland led eight workshops for people with dementia and their carers, featuring more traditional arts activities alongside digital ones, so people could engage in different ways at different times.

An exhibition of work created was held in the Glasgow Dementia Resource Centre, and was attended by the participants, their family, friends and members of the public.

Josie, who cares for her husband Mike, commented: “We participated because I am always trying to give my husband something different to do. I was surprised that he enjoyed the activities so much.”

More info

If you’d like to find out more about art therapy for people with dementia, call the Dementia Helpline or visit the Alzheimer Scotland website www.alzscot.org/art
Dementia really is everyone’s business

People living with dementia tell us they want to remain a part of our communities, both socially and economically. One recent report from the Centre of Economics and Business Research predicts that by 2030 the “dementia pound” will be worth £22.7 billion to the UK economy, so it's vital for businesses and workplaces to recognise the value in being inclusive and welcoming to customers and staff who either have dementia or are supporting someone with dementia.

Since launching the Dementia Friends programme in Scotland in October 2015 we've been making a huge impact with over 650 workplaces, organisations, charities, schools and universities across the country. The popularity of the Dementia Friends Information Sessions has soared as more organisations report the positive impact the sessions are having.

Four reasons why organisations are becoming Dementia Friendly

1. To become a more caring employer
   Hosting a Dementia Friends session can help staff to open up about their experiences of dementia and give bosses insight into the challenges in the personal lives of their employees, building understanding and respect.

2. To improve customer service
   Learning hints and tips on making your environment and service more dementia friendly through understanding the illness better makes staff feel empowered to meet the needs of their customers.

3. To develop reputation
   Improving your service for people with dementia can help grow your reputation as a caring business and emphasise how much you value your customers.

4. To grow business
   When people have a good customer experience they’re likely to recommend you to friends. Becoming Dementia Friendly will help you to retain existing customers, and attract new ones.
HSBC

HSBC Branch Manager, Claire Collington, shares her experience of a pioneering project to make her workplace more dementia friendly.

"Last year, I was invited to take part in My Development Academy (MDA), a project within HSBC to develop our people and leadership skills. My role was the business sponsor – a role to lead and guide a group.

I was really excited to take part in this programme. I was sitting one night watching TV and ‘Living with dementia: Chris’ story’ came on. Nobody I am close to has dementia, but that programme had a huge emotional impact on me, seeing how dementia affected Chris and his family. After watching, I knew I wanted to pitch an idea that would help educate, train and support staff to understand dementia and to support customers experiencing dementia."

"Last June I pitched my idea to over 100 delegates from across Scotland at the programme kick off. My idea was pretty different to the other ideas but my colleagues were quick to see the value in it and get behind it.

The programme ran from June to December 2016 and we’ve gone from having 76 Dementia Friends in HSBC to having over 350, with the goal to have every new member of staff attending a Dementia Friends session."

"Dementia Friends Programme Manager, Anne McWhinnie, and Dementia Friends Ambassador, Stewart Black, visited our call centre in Hamilton. They listened to live calls and gave feedback on how someone with dementia might have felt on that call. They provided tips, including speaking more slowly and checking in with the caller, to make sure they understand what has been said.

‘Colleagues who have taken part in the sessions have said that they feel much more comfortable talking to someone with dementia. They’ve also said they are more mindful that sometimes things might not be as they first appear and that they will be much more patient and understanding when they encounter someone who appears to be having difficulty following a conversation.’"

"I feel really proud of HSBC for running this programme. The MDA group really brought this to life and worked endlessly to ensure they had tangible outcomes at the end. I am extremely grateful for their hard work and dedication. We’ve put something practical in place which will make a difference to our customers who are living with dementia."

Scottish Gas

Indya Nisbet, a 19 year old Customer Service Advisor at Scottish Gas tells us how becoming a Dementia Friend has given her confidence at work.

"Over a year ago I took a call from an elderly gentleman and it became obvious to me that he had dementia. I wasn’t really sure how to deal with that but kept being chatty and friendly. The gentleman provided me with what he thought was his account number but it turned out it was the Alzheimer Scotland Helpline number. Sadly, by the time the call ended I thought I could have done more to help the gentleman. It wasn’t long after that call that I found out Scottish Gas was introducing Dementia Friends Information Sessions for all employees. The sessions were very powerful and showed just how important patience is, and the difference that saying things like ‘don’t worry, let me help you’ can make to a person living with dementia."

"Becoming a Dementia Friend has allowed me to learn what it’s like living with dementia. Within the working environment, it has helped me connect with vulnerable customers and provide them with a more sensitive level of service."

"Since becoming a Dementia Friend I’ve dealt with several calls from vulnerable customers and their carers, including a call from a dementia support worker. Her client had been without an electrical supply for several hours as he was unable to top up his payment card and had lost his key. Remembering what I learned from my Dementia Friend session, I knew that using the pay as you go meter was going to be challenging for the customer and I was able to organise a meter exchange which eliminated the need to top up and the risk of losing his supply."

"I feel that everyone working in a customer service role would greatly benefit from a Dementia Friends Information Session. It makes a real difference when you see things from the perspective of someone living with dementia and I’m glad I’ve become a Dementia Friend."

More info

To find out about having a Dementia Friends Information Session at your workplace, visit www.dementiafriendsscotland.org
Be part of Alzheimer Scotland’s election 2017 pledge on dementia

N o group of elected politicians has more say on the decisions that directly affect people with dementia and their families than our local councillors. They are the only democratically accountable members of the Integrated Joint Boards (IJB) that now run all adult health and social care in Scotland. And even the councillors that don’t sit on those boards have a job to do to scrutinise those who do.

4 May 2017 sees council elections in all 32 of Scotland’s local authorities, with the people of Scotland set to elect 1,222 councillors across the nation. Alzheimer Scotland needs your help to make sure that each one of the newly elected councillors understands what needs to be done to make sure that people with dementia and their carers receive the support and care they need.

We’ve worked together with Alzheimer Scotland members, people with dementia and their carers to develop six priorities we want all councillors to sign up to. But with 1,222 councillors to be elected and many more standing for election, we need all our supporters to get on board with the campaign to make sure they do their job for people with dementia and their carers.

Get on board – get involved

- Find your local candidates
  > Council website, local press, political parties, or ask publicpolicy@alzscot.org

- Tweet them, email them, write on their Facebook pages, attend hustings, speak to them when they campaign and ask them to support our #AlzScot2017 pledge, below
  > Encourage them to take pledge selfies!
  > Tell them why this issue is important to you, how you or those close to you are affected

- Get them to email or tweet their support to
  > publicpolicy@alzscot.org
  > #AlzScot2017

Thank you and good luck!

#AlzScot2017

Voting with dementia

People with dementia and carers often have questions about how to vote with dementia. The most important thing to remember is that 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 with dementia have the right to vote so long as they are able to clearly express their voting choice.

Registering to vote by post or appointing someone to vote on your behalf – a proxy – can help reduce the potential stresses of an unfamiliar environment like the polling station.

For all information relating to voter registration, deadlines and voting preferences, visit www.aboutmyvote.co.uk/register-to-vote.

Contact the Alzheimer Scotland Dementia Helpline on 0808 808 3000 or visit www.alzscot.org/vote to access full information and guidance on voting with dementia.
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.

The commitments set out above are decisions that are the responsibility of each of the Health and Social Care Integrated Joint Boards. Councillors run these boards alongside senior health managers, but it is the councillors who we have the opportunity to democratically hold to account at May’s elections. Together, we can make sure they do their job for people living with dementia and their carers.

This election, let’s get your local candidates to support people living with dementia in your area by making the #AlzScot2017 pledge.

What our councillors should sign up to

#AlzScot2017 Pledge:

I support Alzheimer Scotland’s vision of a nation 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 within a dementia friendly community.

To achieve this, I will work with colleagues in the Health and Social Care Integrated Joint Boards to make sure that:

1. People have a supportive experience of diagnosis, early enough in their illness;
2. People with dementia and their carers get high quality support after their diagnosis;
3. People with dementia and their carers get the integrated and coordinated care they need, where and when they need it;
4. People with advanced dementia and those who care for them have continuity and expert help;
5. Our hospitals and specialists’ services continue to improve the quality and care they offer to people with dementia and their carers; and
6. Self-Directed Support is accessible and efficiently provided to everyone with dementia and carers entitled to it.

People with dementia have the same human rights as every other person. These include the right to be fully included in their community.
Shining a spotlight on post-diagnostic support

This winter, new official NHS statistics issued by ISD Scotland revealed that only two out of five people who had been diagnosed with dementia in the past three years have received a referral for post-diagnostic support, and of those people over a quarter did not complete the programme successfully.

This world-leading guarantee of support was made by the Scottish Government in the National Dementia Strategy 2013–2016. It promised that every person with a new diagnosis of dementia in Scotland was entitled to receive a minimum of one year’s support from a trained and named Link Worker, to work alongside the person, their partner and family over a 12 month period to provide flexible help and support.

Responding to the Dementia Post Diagnostic Support: NHS Board Performance 2014/15 report, Henry Simmons, Alzheimer Scotland, Chief Executive, commented: “The Scottish Government’s post diagnostic support guarantee is widely recognised as a world leading commitment which has led to significant progress in recent years, however the data shows there is still a way to go to ensure that every person diagnosed with dementia is offered this crucial support.

“The gap between this innovative policy development and the experiences of people living with dementia in Scotland is too wide. We appreciate the significant financial challenges faced by the Integrated Joint Boards but we know that this form of early intervention will not only improve the lives of those living with dementia but will also lead to a reduction in inappropriate admissions to residential care, to hospitals and other formal support services, which in the long term have a significant impact on our ability to cope with this rising and urgent challenge. It is exactly the type of support we should invest in if we are to change the balance of care and we would urge all Integrated Joint Boards to maintain, and where necessary, increase investment in their local post-diagnostic support (PDS) services, as a priority, in order to close this gap and deliver on this policy.

“Alzheimer Scotland has campaigned for many years for a person centred and high quality post-diagnostic support to be offered to every person who is diagnosed with dementia. We know that when people with dementia and those who care for them are supported following a diagnosis they can continue to live well in their own homes and play an active part in their communities for longer.

“Getting post-diagnostic support right and delivered to everyone remains a key priority and we will continue to work with the Scottish Government and partners aiming to ensure timely and consistently high quality post diagnostic support is available for every person who receives a diagnosis across Scotland. Put simply, good experiences of post-diagnostic support means a better future for people with dementia – more independence and a better quality of life.”

Grahame lives in Helensburgh with his wife Ann. In April 2015 he was diagnosed with dementia, aged 80.

Over the past year, Alzheimer Scotland Link Worker, Lindsay Voigt, has been supporting the couple.

Ann explained: “When we got Grahame’s diagnosis it confirmed our suspicions. We were connected with Lindsay quite soon after the diagnosis. There was always a feeling of contact and support. We were not alone. I went to Carers’ Information sessions at the Dementia Resource Centre where I met other people in the same situation. Lindsay also told us about what was out there that could be helpful for Grahame.”

Grahame attends a Cognitive Stimulation Therapy group, which Lindsay signposted him to.

He commented: “I enjoy meeting with the other people. It can be funny, friendly and good company. Since my hip surgery I can dance again! I always thought I’d like to be active and it’s good.”

As well as connecting Grahame and Ann with a dementia support network, Lindsay has also offered them advice and encouragement to continue their usual social activities with friends.

“Grahame and Ann are a very sociable
couple and see their friends regularly. They often dog sit for a friend and this is something that gives Grahame great pleasure as he loves dogs. Grahame loves going to the local cinema and recently enjoyed a live stream of Andre Rieu. He has also been going swimming as rehab for his hip replacements. I’m always here if Grahame and Ann have any questions or concerns about how best to keep these activities going.”

Karen Lau, whose partner Frani has been diagnosed with Frontotemporal dementia (FTD), said: “We first met Susan, our Link Worker, at the point of Frani’s diagnosis when we felt quite lonely and isolated – so Susan coming along was a great gift. She came into the house, gathered us up and gave us all the information we needed, but not too much, just enough to keep us going. “Frani gets on extremely well with Susan and she gets on well with the whole family. She links us up with every service we need so I’m not wondering where I’m going. I don’t have to worry – she’s my first port of call. I can give Susan a call and things are fixed – and that’s very important and reassuring. Having someone say it’s not good, but it’s going to be okay – that’s a really nice thing to have happen.”

More info

If you would like to get involved in ensuring post-diagnostic support is a priority in your area ahead of the 2017 Scottish local elections, please get in touch by emailing info@alzscot.org and we will connect you with your local Policy and Engagement Manager. By being part of the network you will have the opportunity to take action and make a real difference to lives of people newly diagnosed with dementia, their families and carers.

This spring, Alzheimer Scotland released a short, powerful film highlighting the benefits of post-diagnostic support and Link Workers. The film is introduced by former First Minister, Henry McLeish, and features interviews with people with dementia and their carers, Link Workers, a well-respected researcher and a commissioner.

The film is primarily aimed at decision-makers within Integrated Joint Boards, and urges them to continue, and consider increasing, support for crucial post-diagnostic initiatives for people living with dementia in their communities.

The video can be viewed online at www.alzscot.org/linkworkervideo
Although not every trainee Allied Health Professional (AHP) will become a dementia specialist, all are likely to have some contact with people with dementia. It is important that this wider group of new AHPs are confident Dementia Informed and Skilled Practitioners.

**Inspiring future dietitians**

Allied Health Professional Practice Education Facilitator, Adrienne McDermid-Thomas, tells us about a recent initiative which saw student dietitians learn from experience at Alzheimer Scotland.

Last year we welcomed 15 second year dietetics students from Queen Margaret University (QMU) to increase their understanding of dementia by becoming Dementia Friends and visiting an Alzheimer Scotland Dementia Café.

Following their visits, QMU Programme Leader Sarah Smith and I caught up with the students to assess the educational value of this new learning experience.

I am pleased to say we found that introducing dietitians to people with early stage dementia at the outset of their training enabled both the students and people with dementia to work together to develop a better understanding of dietetics and dementia. Furthermore, the students were inspired to approach their work creatively, patiently and in a person centred way. In a café environment, trainees were able to consider how dementia may affect the person’s relationship with food and to learn from experienced Alzheimer Scotland staff.

It was wonderful to see participants gaining a broader understanding of dementia. Of particular interest was their recognition of the importance of clear communication. One student commented: “During my visit it was important to ensure that each individual I spoke to wanted me to talk to them and to know that they fully understood what I was talking about. If they didn’t understand, I would ensure to explain to them differently.”

We’re now working with Sara at QMU to see whether this experience can become a fixture in the dietetics course, and what additional opportunities there might be to offer more in depth educational experiences.

**Inspiring future physiotherapists**

2016 saw Alzheimer Scotland’s first Physiotherapy student, Amy Murray (QMU), spend two days a week at the Fife Dementia Resource Centre (DRC) during a six week placement shared with NHS Fife and supervised by an NHS Physiotherapist in partnership with the Alzheimer Scotland Dementia Advisor. Amy brought a physiotherapy approach to existing exercise groups and environmental audits at the DRC and gained an understanding of how she could work differently to meet the needs of the people she worked with.

We are also working with Robert Gordon University and Glasgow Caledonian University to further integrate physiotherapy placements into Alzheimer Scotland services.

**Connecting people, connecting support**

Allied Health Professionals from across a wide range of disciplines have come together to generate a new policy guidance document called ‘Connecting people, connecting support’.

The final policy document will be published later this spring and will share how rehabilitation skills and expertise of AHPs can help families living with dementia. It will focus on five key elements to maximise the AHP contribution to dementia services that are tailored to the needs of individuals, reflect the best available evidence and are delivered by a skilled AHP workforce.

Look out for updates on social media or email ehunter@alzscot.org to request your copy.
Introducing Alzheimer Scotland’s new Tech Team

If we think about technology as being anything with a plug or battery, then it’s easy to see how much tech we use every day: mobile phones, kitchen appliances, activity trackers, iPads and even online shopping. The list is endless, but what about technology for people living with dementia?

Technology can support people living with dementia to manage risks, improve quality of life and stay in their own home for as long as possible. For example, home health monitoring, cooker controls, medication pill dispensers, video messaging apps, GPS and location technology. But where do we find out about these things?

Help is at hand from the Tech Team. Get in touch to access resources, including online videos, leaflets and useful links and go to www.dementiacircle.org to see feedback from our testing circles (people living with dementia and their carers who have tried and tested products for us) and to watch video clips about technology and everyday domestic products that people have found helpful.

Alzheimer Scotland’s Technology Coordinators are funded by the Scottish Government’s Technology Enabled Care workstream for two years. The aim of this programme is to increase uptake and use of technology amongst health and social care providers, in order to support people to live well and safely at home.

Dementia Circle

The Bridgeton Resource Centre is the latest venue to witness some real live product testing with Dementia Circle. Meeting on the first Wednesday of each month, this is a group that tackles the practical challenges of dementia. It is open to carers, family or people with a diagnosis.

This January, our intrepid team helped destruction test a garlic press, amid much hilarity, as we tried to find the optimum pill crusher. We did find a cracker see our Facebook page for details!

We explored our concerns at connecting to the net for the first time and how to best take advantage of conveniences like internet shopping. We also took on the challenge of setting up some key safes and luckily managed to retrieve our keys safely!

If you’d like to become a tester of everyday technologies and share your views, get in touch on tec@alzscot.org.

Technology Charter for People Living with Dementia

Since we launched the Technology Charter for People Living with Dementia in Scotland (December 2015), we have been busy presenting the Charter at local and national conferences, running masterclasses and delivering workshops.

We have been raising awareness of how everyday technologies can make a difference to the lives of those living with dementia by speaking to the public, a wide range of organisations, nursing students, Dementia Champions, Dementia Ambassadors and Post Diagnostic Support Workers.

Organisations and businesses are invited to sign up to the Charter and commit to promoting the use of technology in dementia care. Sign-ups so far include Storii, Outside the Box, EIO Card, Loretto Care, RNIB Scotland, Video3 Media, Keysafe and MindMate.

This year we have exciting plans to work with NHS Education Scotland, Scottish Social Services Council, universities and dementia friendly communities. If your organisation would like to get involved, email tec@alzscot.org.
Blue Badge pilot scheme

The Blue Badge scheme helps you park closer to your destination if you have a disability. Alzheimer Scotland Dementia Helpline Manager, Elaine Harley, explains how a new pilot project is making it easier for people with dementia to access this important scheme.

Many of you will know that getting a Blue Badge for someone with dementia has been a challenge, unless the person qualifies under physical disability criteria. In 2013, Transport Scotland started to gather information on extending the eligibility criteria for the scheme to include people with significant cognitive impairment or with a diagnosed mental health issue. The responses received indicated that there certainly was a need to extend the scheme to people whose physical mobility might be fine but whose cognitive impairment meant that they were no longer safe in busy traffic areas. It was clear that many in this group and their carers would benefit from holding a Blue Badge, so the driver of the vehicle could park in disabled spaces much nearer to shops and other community facilities.

On 1 April 2016 a pilot project was set up to extend the standard Blue Badge scheme to anyone with a diagnosed mental health condition who receives certain social security benefits and whose lack of awareness of danger from traffic is likely to compromise the safety of the person, or other persons, during journeys. The initial pilot was for a year, but this has now been extended for a further six months and it will run until September 2017. From the start of April this year, Scottish Local Authorities will also have discretionary power to issue a badge for three years instead of just one.

There have been a number of teething troubles with the scheme, and publicity for the pilot has been patchy across Scotland. Our Dementia Advisors, Link Workers and local services have worked hard to promote awareness of this pilot. If you know someone who would benefit from having a Blue Badge, please get in touch with the Blue Badge team at your Local Authority or with an Alzheimer Scotland service.

Alzheimer Scotland is included in a working group monitoring this very welcome extension to the scheme, and we’re keen to hear your stories about ease of applying and the difference having a Blue Badge has made. Please get in touch and let us know your experience.

"The responses received indicated that there certainly was a need to extend the scheme to people whose cognitive impairment meant that they were no longer safe in busy traffic areas."
Join dementia research

Alzheimer Scotland Corporate Fundraiser, Natasha MacKinnon, tells us about her dementia research experience.

I’ve always been interested in the research that we fund but because I’m under 30 I thought it was unlikely I’d ever be picked to participate. So I was surprised when Lucy Hiscox – PhD Candidate at the University of Edinburgh – got in touch with me and invited me to participate in a study via Join Dementia Research, which aimed to measure how sound waves move through the brain and how elastic or healthy the brain is. Lucy will compare my test results with older healthy brains as well as brains affected by dementia so that we can better understand the process of the disease as it affects the brain and see if we can identify any earlier signs present in the brain.

It felt really empowering to know that I would be taking part in research that might shed more light on the causes of dementia. I arrived at the Clinical Research Imaging Centre and met with Lucy who checked my eligibility against various medical conditions. The study I was involved in meant that I was going to be in a MRI machine – Lucy would place a pillow under my head which would be filled with air and vibrated for different periods of time with varying strengths of vibration while the scans were going on.

I imagine that some people might get nervous at this stage but I had several operations during my childhood so hospital settings and machinery don’t really faze me. I found the experience quite relaxing actually as you’re fitted with earplugs and then you have headphones over the top playing music. If it hadn’t been for the vibrations and the crick in my neck I think I would have fallen asleep!

Afterwards, Lucy did some basic cognitive tests to check my recall and brain function. These involved recalling word-pairs that Lucy had said to me up to 10 minutes ago as well as a rather complex adult reading test!

While it is possible for people to live well with dementia for many years unfortunately there is currently no cure. It means a lot that I’ve taken part in research which may help pinpoint the cause of dementia which could also help develop future treatments and potentially even prevent the disease for future generations.

Our knowledge of dementia currently lags behind that of other major conditions, such as cancer or heart disease. Sign up now and help us to close this gap. It’s quick and easy to sign up online and they’re always looking for participants 18 or over, with and without dementia.

To sign up to Join Dementia Research, visit www.joindementiaresearch.nihr.ac.uk or call the Alzheimer Scotland Dementia Helpline on 0808 808 3000.
Realising lifelong dreams beyond a dementia diagnosis

Joan Porter has had her first books published aged 84, she’s the matriarch of a large and loving family, and she’s showing people that it is possible to make the most of life with dementia.

Now, aged 85, Joan Porter has found her 15 minutes of fame. When we arrive, Joan is in her favourite chair cradling her three-week-old great grandson, Findlay, while her four daughters, granddaughters and great grandchildren gather round for a photo shoot with a health and lifestyle magazine.

The reason for all this interest in Joan is that she’s just published her first books of children’s verse, and she has been living with dementia for the past four years.

Sitting in her busy living room, Joan, a former playgroup leader, comments: “I feel like the old woman who lived in the shoe!” She doesn’t let fame go to her head however, confessing that she’d rather be reading her stories to a group of children than discussing their publication or what it’s like to live with dementia. “I don’t really think about it. The dementia isn’t like a headache, but I can feel it – it’s a weight, a heaviness in my brain, but I just get on with things,” she tells us.

Joan’s eldest daughter Doreen tells us about her mum’s diagnosis: “It was a few years ago when we began to notice changes in mum. We got mum signed up to one of the studies at the Glasgow Memory Clinic, as I’d heard that the process of diagnosis was often faster as part of a study. In 2012 mum was diagnosed with Vascular Dementia and Alzheimer’s Disease.

“At the time of diagnosis, mum was living alone in our home town of Tarbert and was beginning to struggle living so far from the rest of the family. It was a very difficult decision for us all to move
mum closer to us, but it was fortunate that a flat became available where my husband and I live at Trust Housing Association. It’s great to be so close, but we have separate flats so we can have a bit of space too.”

“It was when we were packing up mum’s house to move here that we rediscovered all her stories written down. It was so nice to read them all again after such a long time.”

Joan’s daughter Lynne explains: ‘Mum first invented all of her characters and stories back when we were children, but they were never written down. When she retold the stories to the children at nursery they begged her to let them take the stories home, so she wrote them out by hand for them. When dad was alive he always encouraged her to get them published but for one reason or another it never happened.’

The daughters began approaching publishers with their mother’s stories and soon heard back from Cathy Wilson at Ailsapress, a small independent publisher based on the Isle of Islay. She was keen to work with the family and brought illustrator Jessica Excell on board to bring the characters to life.

In October 2016 the first books were rolling off the press.

Since then, Joan has been invited to speak about her book and what it’s like living with dementia: people are really interested. She’s most herself when she’s in the classroom with a group of children and telling them her stories – she walks into the room and has them all captivated! Mum does also talk to the children about dementia and explains it so they can understand. Some of the children have grandparents with dementia. Mum had a conversation with one little girl who said ‘My granny needs help remembering what day of the week it is’ and mum replied ‘me too!’ It makes it normal for the kids and it is good for people to see that you can still do things when you have dementia.”

Arlene’s passion for raising awareness has inspired her to get her friends together and challenge dementia this summer. Arlene says: ‘Last year I was toying with the idea of doing something to honour mum so I messaged a few friends and got a brilliant response. We decided that we would tackle the West Highland Way, covering 96 miles in four days – we’re calling it our Jaunt for Joan! I’ve been bowled over by everyone’s enthusiasm to get involved, we’ve even had an old family friend sponsor the event so a huge thanks goes to Allan Bryden at GP Environmental Ltd. we wouldn’t be able to do the challenge without him. We’ll be setting off on Friday 26 May and will reach the finish line on Monday 29 May, which is the start of Dementia Awareness Week!’

What next for Joan? Well, she says she’s definitely got a few more stories in her. ‘Sometimes when it’s boring on long nights I do tell myself the stories again and make up new ones. I’d like to write some more down. So who knows… watch this space!’

You can buy Joan’s ‘Little Terry Tiddlemouse’ books online through Waterstones and Amazon. Search ‘Little Terry Tiddlemouse’.

Read more about Arlene’s West Highland Way challenge and to sponsor the team, visit www.justgiving.com/fundraising/ajauntforJoan
Youth volunteering

Across Alzheimer Scotland we have over 700 volunteers who generously give their time to support our services and bring friendship and understanding to the people we support. In this edition, we’re shining a spotlight on our young volunteers.

Lucy, from West Lothian, age 17
Volunteer befriender visiting a residential care home

I got involved with Alzheimer Scotland through a teacher who recommended volunteering as a befriender with the charity.

Being a volunteer allows you to make an impact on lots of people’s lives and you get a lot out of it too. It makes you happy when you have helped someone with Alzheimer’s to engage in a game with you. People just need someone to talk to them, listen, empathise and be there for them.

A resident recently said to me “Who are you here to see?” and I was like “You, if you want to chat?” and the smile lit up her face as she looked so grateful and replied “Really?” The residents gain confidence, as they are able to do activities and remember things such as my name, which pleases them to no end!

Through volunteering I have gained more confidence and became more independent. I suffer from depression and struggle sometimes, but to know I can make a difference in someone’s life makes me feel like I really am worth something.

Katie, from Erskine, age 20
Volunteer befriender in Alzheimer Scotland Dementia Resource Centre

From the age of 14 up until my 20th birthday I helped care for my grandpa, who had Alzheimer’s. Constantly being around someone with dementia became so normal for me that when my grandpa passed away I worried about not having that sense of normality in my life anymore.

I knew that I wanted to help other carers, so I got in touch with Alzheimer Scotland’s Forget Me Not project and received fantastic training.

I volunteer at the under 65s cafe every Monday. It’s a really relaxed environment where everyone can sit with a cup of tea and just chat about their week. Sometimes this involves speaking about dementia, but more often than not, it’s just a time for people to comfortably share news and talk about hobbies or upcoming events.

I have found it quite therapeutic being able to remain in the company of people who cope with dementia on a daily basis. I feel very privileged to be afforded the opportunity to hear about their lives and connect with their families.

Helensburgh Youth Volunteers

Last February, Community Fundraiser Bronwyn O’Riordan started recruiting young volunteers to help with fundraising and to engage younger people in the activities of the new Helensburgh Dementia Resource Centre.

So far 24 young volunteers aged between 15 and 20 have signed up. Each of the group members has taken part in Dementia Friends training. Every month they organise a fundraising activity and they support staff with fundraising and awareness events. To date they have raised over £21,500 at events including bucket collections and seasonal fundraisers. They also support the Dementia Resource Centre’s cafe or groups.

Seventeen year old Naomi is one of the volunteers. She commented: “I wanted to volunteer to help make a difference to those with Alzheimer’s and dementia, whether it was through fundraising or group work. I also wanted to raise awareness for what Alzheimer’s is and to try and remove any stigma surrounding it. I have also been able to gain great advice from those who have dementia, and have learned to never live life with regrets. I have had so many different experiences as a volunteer.”

More info

If you would like to find out more about volunteering with Alzheimer Scotland, visit www.alzscot.org/volunteer
Where to now? The future of research beyond drug trial disappointments

This February, Merck was the latest pharmaceutical company to announce disappointing news that its clinical trials into Verubecestat, a new Alzheimer’s drug, had failed at a late-stage clinical study. This followed similar news from Eli Lilly announcing that one of its experimental medicines, Solanezumab, had been similarly unsuccessful in a late-stage trial of patients with mild Alzheimer’s.

Both drugs had been based on the amyloid hypothesis, which theorises that the important factor is a protein known as beta-amyloid which builds up and forms plaques in the brains of people with Alzheimer’s.

The failure of both of these clinical trials, following several other anti-amyloid drug trials, has caused some within the scientific community to question whether beta-amyloid is central to the development of Alzheimer’s in most people, rather than a secondary process and, if that is the case, researchers should be turning their attention elsewhere. Failure of previous trials has been put down to including people who do not have substantial amounts of amyloid deposited in their brains, and treating at too late a stage when the damage caused by amyloid has already happened. More recent trials have been careful to include only people shown to have amyloid on brain scans or in a lumbar puncture, and have focussed on intervening at an earlier stage when the full-blown symptoms of Alzheimer’s have yet to develop. Nevertheless, to some researchers the vast amount of resources that have been poured into reducing amyloid burden has appeared like the pharmaceutical industry putting all its eggs in one basket.

Professor John Starr, Director of the Alzheimer Scotland Dementia Research Centre, comments: “Ongoing clinical trials of anti-amyloid drugs in those who are yet to develop significant symptoms are important as we do not yet know if they will work. If they do, they will have a major impact. However, the pharmaceutical industry should not abandon those who have developed the clinical disease, where different approaches will be required. For example, we do not have very good treatment of symptoms such as agitation, depression and apathy, all of which have a major impact on those with dementia and their families. Finding treatments that can improve these symptoms more effectively would be very valuable”.

WHO recommends Global Dementia Plan

Steady progress is being made on the Global Plan on the Public Health Response to Dementia 2017–2025. In January, it was agreed that the plan will be placed before all countries at the World Health Assembly in May 2017.

The plan supports the urgent message that governments must develop national plans to address the impact of dementia in their communities and urges that member states must prepare now to meet the targets of the plan in partnership with people with dementia and Alzheimer associations everywhere.

Study links living near busy roads to dementia risk

In January, a research study from the Public Health Department in Canada found that dementia is more common in people who live within 50 metres of a major road than those who live further away, according to a study looking at 6.6 million people.

These findings are consistent with other research on air pollution and dementia but the mechanism underlying the association between air pollution and dementia remains unclear. Overall this study will help inform future research and a better understanding of the environmental risk factors and help us develop risk reduction strategies.

Alzheimer’s Disease International conference

Alzheimer’s Disease International will hold their 32nd International Conference in Kyoto, Japan from 26–29 April 2017. The conference will focus on the latest research, care and policy issues under the theme of ‘Dementia: Together towards a new era.’

Jan Beattie, who leads Alzheimer Scotland’s Workforce Development, will represent Alzheimer Scotland at the conference and at the ADI Council meeting. Jan’s presentation is about developing a confident workforce to deliver post-diagnostic support. Jan will also be visiting examples of dementia support and care in the country that is recognised as being a world leader in dementia support and for its positive approach to older people.
You’re invited! Dementia Awareness Week 2017
Monday 29 May – Sunday 4 June

Join thousands of people all over Scotland as we shine a spotlight on what it’s like to live with dementia.

Dementia is a big deal and we want to get Scotland talking about it! From Monday 29 May – Sunday 4 June, people all across Scotland will be taking part in seven days of awareness raising, conversation, fundraising, support and campaigning.

This year we’ll be taking a look at dementia and friendship. Anecdotally we hear that many people living with dementia and their carers feel that they have lost friendships following a diagnosis. People can find it difficult to know how to react when they hear the news that their friend has dementia.

During Dementia Awareness Week 2017 (DAW2017) we’ll be out and about in communities and on social media with some simple messages that can help people feel less awkward, embarrassed or uncertain when they find out that their friend has dementia.

Tea & Blether

A cuppa and a catch up is a good place to start when you hear the news that someone you know has dementia. That’s why we’re asking you to share a cup o’ kindness with us during DAW2017. Hold a Tea & Blether to get the conversation flowing, share your experiences and raise some vital funds to support Alzheimer Scotland services. Visit www.alzscot.org/daw2017 now to order your Tea & Blether fundraising pack.

Information packs

We also have information materials available which could be used by community groups and charities, schools and universities, hospitals, health centres, places of worship and much more. If you would like some information resources for your workplace or group, please visit www.alzscot.org/daw2017 to order your pack.

We look forward to seeing you all during Dementia Awareness Week 2017!
Challenge Dementia

Spring has sprung, the nights are getting lighter and some of us will feel that it is about time we committed to that New Years Resolution we made to get fitter and healthier. If you’ve got a fitness goal in mind for 2017, give yourself some solid motivation by taking on a challenge of your choice to raise funds for Alzheimer Scotland and really Challenge Dementia in Scotland.

This year, Michelle McKee from Paisley led the charge to get people signed up to do something to challenge themselves and raise money for Alzheimer Scotland. The 34 year old amateur runner has signed up to run two marathons within two months in memory of her mum Caroline, who passed away with dementia last November, just 20 days before her 60th birthday.

Encouraging everyone to get involved in a personal challenge, Michelle says: “From the beginning, running has been my saviour. It helps with anger, sadness and a list of other emotions you encounter when watching a loved one suffer.

I began competing in races to raise funds for Alzheimer Scotland. The support before and during the race was incredible. Everyone wearing the Alzheimer Scotland logo top on the day either high-fived me, ran next to me, shouted words of encouragement or even hugged me. We were like a family and I was completely overwhelmed. The feeling that I had that day was like no other. It was as if we all understood each other. I was sad, however, to notice how few runners for Alzheimer Scotland there were in comparison to other charities.

“My ultimate dream would be to witness a sea of purple at every event I attend in the future, to be part of a colossal team, a purple army.”

If you want to join Michelle and do your bit to Challenge Dementia in 2017, we recommend these late summer/early autumn events. There’s still time to get fit over the summer months!

You can also browse all of our events at [www.alzscot.org/sponsored_events](http://www.alzscot.org/sponsored_events) or you to turn any event into a challenge that raises money for Alzheimer Scotland, just get in touch at events@alzscot.org to find out more.
Dementia in Scotland

Hello, I’m Buddy the Dog and I want to tell you all about Memory Walkies.

Memory Walkies is a great new way for us dogs and our K9 friends to help make sure nobody faces dementia alone.

I need Top Dogs to gather a pack of canine friends for a fun sponsored walk.

As the number of people living with dementia in Scotland continues to rise there has never been a more vital time to support the work of Alzheimer Scotland. People living with dementia and their carers tell us they need support and care today.

100% of funds raised by Alzheimer Scotland stay in Scotland and we need to continue to reach out to people living with dementia now so that they can live well in their own homes and communities for as long as possible.

By coming together, we can meet the challenge of dementia and create a better future for all of us.

So grab your owner and get them to sign us up today! Download your free toolkit at www.alzscot.org/memorywalkies

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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.

### April
- Sun 30: Glasgow Kiltwalk

### May
- Sun 14: Aberdeen Baker Hughes 10k
- Sun 21: Stirling Marathon
- Sat 27/Sun 28: Rotary Club of South Queensferry
- Sun 28: Forth Rail Bridge Abseil

### June
- Sun 4: Great Women’s 10k
- Sun 4: Aberdeen Kiltwalk
- Sat 17/Sun 18: Tough Mudder, Drumlanrig Castle
- Sat 17/Sun 18: Edinburgh Night Ride

### July
- Sat 29: Big Fun Run, Glasgow
- Sat 29: Dog Jog, Glasgow
- Sun 30: Big Fun Run, Edinburgh
- Sun 30: Dog Jog, Edinburgh

### August
- Sun 20: Dundee Kiltwalk
- Sun 27: Great Aberdeen Run

### September
- Sun 10: Great North Run, Newcastle
- Sun 10: Pedal for Scotland, Glasgow to Edinburgh
- Sun 17: Edinburgh Kiltwalk
- Sun 24: Scottish Half Marathon, East Lothian
- Sun 24: Loch Ness Marathon

### More info

Find out more and book tickets at www.alzscot.org/fmnball

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Supergroup Boyzlife to help raise vital funds for dementia

Brian McFadden (Westlife) and Keith Duffy (Boyzone), part of the multi-platinum, record breaking bands, Westlife and Boyzone, have joined forces to create Boyzlife to celebrate the success of the two chart-topping bands.

The duo who are currently on tour will headline Alzheimer Scotland’s annual ‘Forget Me Not Ball’ on 9 September at The Marriott Hotel in Glasgow.

Keith Duffy, said: ‘We both love Scotland and we’ve always been made to feel so welcome all over the country so we are looking forward to performing at Alzheimer Scotland’s Forget Me Not Ball in Glasgow this September. We hope the charity raises vital funds on the night to continue to do amazing work.

‘Dementia is something we know that so many of our fans will be dealing with on a daily basis whether it is their grandparents, parents or something they are living with themselves. Our hearts really go out to everyone coping with dementia in their lives. It is such a heartbreaking illness.’
Davidsons Chemists

Our friends at Davidsons Chemists raised an incredible £16,293.89 for Alzheimer Scotland during our 2016 ‘Charity of the Year’ partnership. Fundraising efforts included bake sales, sweepstakes and amazing staff challenges such as the Forth Rail Bridge abseil. Staff members across the 28 branches also became accredited Dementia Friends. We would like to say a big thank you to all staff and customers at Davidsons Chemists for their generosity.

BNP Paribas

We are delighted to announce that BNP Paribas offices in Scotland raised a fantastic £20,436.09 over the course of our 2 year partnership. Generous employees went the extra mile to support us through monthly dress-down days, bake & book sales and challenge events. They also got involved in our Dementia Friends programme, raising awareness of dementia throughout their organisation. All of us at Alzheimer Scotland are hugely grateful for this support and would like to say a special thank you to the charity representatives across the BNP Paribas offices who helped their teams reach this total.

Crystal Ball

The annual Crystal Ball was held at the prestigious Prestonfield House Hotel on Saturday 26 November. Hosted by the inimitable Arlene Stuart and featuring entertainment from The Flavours, opera singer Ciara Harvie and comedian Peter Brown, this glitzy fundraising extravaganza raised a phenomenal £26,000 for Alzheimer Scotland. We would like to say a big thank you to our generous attendees and also the dedicated committee and venue for making this such an incredibly successful event. The 2017 Crystal Ball will again be held at Prestonfield on Saturday 25 November. So pop the date in your diary, keep ahead of the crowds and get in touch to reserve a table today!

Rowlands Pharmacy

We were delighted to be supported by all Rowlands Pharmacies in Scotland this February who encouraged staff to open conversations with customers around dementia and signpost them to our 24-hour Freephone National Dementia Helpline for additional support. They also sold a collection of our point-of-sale items including our pin badges and wristbands! Thanks so much to Rowlands for helping to ensure that nobody has to face dementia alone.
Deborah and Jennifer have raised over £6,000 for Alzheimer Scotland through a number of different events, including a trip to China last October to complete The Great Wall of China Trek. They are already planning more events for the coming year!

Stephanie from Edinburgh organised a series of bucket collections throughout 2016 and raised a fantastic £870 and has even bigger plans for 2017. Thank you for giving up your time to support Alzheimer Scotland!

This January, supporters raised over £3,000 at a Strictly Dance Extravaganza held at the Festival Theatre in Edinburgh. Here are some young ballroom dancers from the Millar Dance Studios meeting Caroline and Sylvia from Cairdean House Care Home, who accompanied a pair of ballroom dancing enthusiasts from the care home on this magical night out.

Rory Fisher raised £690 by dying his hair purple for Alzheimer Scotland. Rory wanted to raise the money after his granddad died from Alzheimer’s disease last summer and his grandma is now living with advanced Alzheimer’s.
This January, Helensburgh Oratorio Choir held a Big Sing event in aid of Alzheimer Scotland and raised a superb £1,000. Here are Alicia and Jonathon from the Choir handing over the cheque to Community Fundraiser, Bronwyn (right).

Donations aren’t always money – here is the cast of ‘All Shock Up’ as performed by the fabulous Cecilian Society, who gifted tickets to our services across Argyll and Clyde. Thanks for the excellent experience!

Eleven year old Logan Copeland asked his friends and family for donations in lieu of birthday gifts, raising £200 in memory of his Nana.

Employees from the University of the Highlands and Islands have raised over £6,530 for Alzheimer Scotland, through events like the 5 x 50 challenge, Christmas raffle and Christmas jumper day.

Huge thanks to Jennifer Chalmers (left) and her customers at the Premier Store in Castlepark for their donation of £870 this February. They have supported our Irvine Services for many years with customers donating spare change and a book exchange donation scheme. Marie Thomson (right), the manager at our Irvine Services, popped in to say thank you and accept the donation.

Former Scotland International goalkeeper, Andy Goram was the guest speaker at the Football Quiz Night which raised £17,000 to be shared between Alzheimer Scotland and Ayr United Football Club Youth Academy.
Dear reader,

We’re keen to make sure that our magazine, Dementia in Scotland, provides you with interesting, relevant and quality content. We’d love to know a bit more about who you are and why you read the magazine. What fascinates you, what information you find helpful and what kinds of articles you enjoy.

If you’ve got a few minutes, it would be great if you could fill in this quick survey and return it to us by Friday 28 July. The survey is also available online at [www.alzscot.org/readersurvey](http://www.alzscot.org/readersurvey).

Complete this survey and you have the chance to win a beautiful Alice in Wonderland afternoon tea hamper from Whittard. For terms and conditions for the prize draw please see [www.alzscot.org/readersurvey](http://www.alzscot.org/readersurvey).

Thanks in advance for your assistance!

### About you

I identify as:
- [ ] Female
- [ ] Male
- [ ] Other

Age:
- [ ] 18–24
- [ ] 25–34
- [ ] 35–44
- [ ] 45–54
- [ ] 55–64
- [ ] 65+

I read Dementia in Scotland because:
(select as many as apply)
- [ ] I have dementia
- [ ] I am a carer for someone with dementia (including partners and spouses)
- [ ] I work in a dementia-specific role
- [ ] I work in a health related profession
- [ ] I am an Alzheimer Scotland member
- [ ] I am a student
- [ ] I work for a corporate supporter
- [ ] I work for Alzheimer Scotland
- [ ] I use Alzheimer Scotland services

You can complete this survey anonymously, but if you wish to be entered into our free prize draw, please complete your contact details below:

Name:

Address:

Phone number: [ ] Postcode: [ ]

Email address:

### About your reading habits

How long have you been a reader of Dementia in Scotland?
- [ ] Under a year
- [ ] 1–2 years
- [ ] 2–3 years
- [ ] 3–5 years
- [ ] 5 years or more

How would you describe your approach to the magazine?
- [ ] I read the magazine from cover to cover
- [ ] I just read articles that are relevant to me

How do you usually read Dementia in Scotland?
- [ ] Online
- [ ] In print
- [ ] Both
Here are some content types that appear regularly in the magazine. Please tell us how often you read or look at them:

<table>
<thead>
<tr>
<th>Content Type</th>
<th>Every issue</th>
<th>Most issues</th>
<th>Some issues</th>
<th>Never</th>
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<tr>
<td>Chief Executive’s foreword</td>
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<td>Fundraising news</td>
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<td>Interviews with/features on people living with dementia</td>
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<td>Dementia Friends and Dementia Friendly Community news</td>
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<td>Policy news</td>
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What would you like to see more of in the magazine?

(Please select your top three)

- [ ] Product reviews
- [ ] Information/top tips/advice for living well with dementia
- [ ] Articles on legal issues (Power of Attorney, Guardianship)
- [ ] Policy updates
- [ ] Human interest stories
- [ ] Alzheimer Scotland staff profiles (a day in the life of...)
- [ ] Guest columns
- [ ] Information about research
- [ ] Fundraising stories
- [ ] Other

Overall, what do you think about the length of articles in the magazine?

- [ ] Too short
- [ ] About right
- [ ] Too long

Do you prefer:

- [ ] Articles that are mainly text
- [ ] Articles that have pictures

What do you think of the text size in the magazine?

- [ ] Too small
- [ ] About right
- [ ] Too large

The magazine is published three times a year. What do you think about the frequency of the magazine?

- [ ] I would like to see more editions
- [ ] I think it is about right
- [ ] I would like to see fewer editions

What do you think about the overall length of the magazine? It is usually around 32-36 pages long

- [ ] Too short
- [ ] About right
- [ ] Too long

Thank you for completing this survey!

If you wish to share any additional thoughts you have on the magazine, please feel free to include another sheet of paper with your feedback.

Please return this completed survey to:

Reader survey, Alzheimer Scotland, 160 Dundee Street, Edinburgh, EH11 1DQ
Are you up for Memory Walk Scotland 2017?

Then get your name down!
Registrations for our annual Memory Walks open in May. Make sure you don’t miss out!
Sign up to our Memory Walk alert list now so you’re first to find out when booking goes live.
Who will you walk for? www.memorywalksscotland.org