Dementia in Scotland



Winter 2023 - Issue 107



We're here for you this winter and always.



We want to reassure you that Alzheimer Scotland will remain here for you this winter:

Alzheimer Scotland's 24 hour Freephone Dementia Helpline

Our Helpline is there for you day or night, whenever you need us. Our highly skilled team will offer a listening ear and emotional support, provide information and will signpost on to other supports if necessary. Call on **0808 808 3000**. You can also contact our Helpline team via email on helpline@alzscot.org



National Dementia Advisor Service

If you need information, advice or advocacy in dealing with issues relating to dementia, our National Dementia Advisor Service is here to help you. As with our Helpline, the service is funded by Alzheimer Scotland from the generous donations and fundraising activities of our thousands of supporters. The service is available from 9am - 5pm, Monday to Friday, and can help with a wide range of issues such as accessing health and social care support, help with complaints, power of attorney, guardianship, and money and legal matters. You can call the service on **0300 373 5774** (charged at a local call rate), or email **NDAS@alzscot.org**



Warm spaces

We know that energy and other costs of living remain a worry for many people. All our 25 Centres are here to welcome you and offer a warm space and a cuppa. Where possible all our centres will be providing extra groups and activities. This might be additional Tea & Blether sessions or Coffee Catch Ups where a warm welcome, company and a hot drink awaits. Remember our Centres are also open when no groups are running so do drop in and bring a friend or family member. To find out more about how we can help, and what's on at your local Centre, please go to our website at www.alzscot.org/drc or contact Alzheimer Scotland's National Dementia Advisor Service on 0300 373 5774



Issue 107 - Winter 2023 Welcome

Contents

- 4 Local news
- 6 Our support
- 8 Active Voice
- 10 Winter campaign

- 12 Campaigning for change
- 13 Events
- 14 Innovations & initiatives
- **15** Brain health update
- 16 Your support
- **18** Exciting developments

Welcome

Welcome to the winter edition of Dementia in Scotland magazine.

We are delighted to share updates from across our support and services, from the opening of a new Brain Health Service and Clinic in Aberdeen (p15) to our innovative virtual reality projects (p14).

On 21 September, World Alzheimer's Day, we launched our new National Dementia Advisor Service (p18). This provides responsive, high-quality information, advice and advocacy support relating to all aspects of brain health and dementia. The team of highly skilled Dementia Advisors are available to answer general enquiries, but also to help people work through more complex issues. The team have supported over 400 enquiries in a short space of time, indicative of the need for such a service.

We are very aware of the challenges and difficulties the winter months bring to the people we support. Our Centres across Scotland offer a warm space and a warm welcome. We will also be providing as many additional groups and activities as we possibly can. You can read more about our winter support to the left of this page.

You will read on p18 about further developments on our Student Research Programme.

We are thrilled to be inviting proposals for a second round. 'Research' is the focus for our annual charity fundraising appeal. In our 'We're All In' campaign, we celebrate the idea that each of us, in our own unique way, contribute to the multifaceted landscape of dementia research and recognise that no matter how you choose to be involved, your contribution is a vital part of the dementia research picture. A big thank you to Kenny, Rynagh and Willy for their first-class contributions to the campaign messaging. And thank you to every single person who has supported our charity this year – every penny raised in Scotland, stays in Scotland. It is vital services like our 24 hour Freephone Dementia Helpline and new National Dementia Advisor Service

which are wholly funded by the generous donations and fundraising activities of our supporters. Thank you.



Henry Simmons, Chief Executive

We would like to hear your thoughts on Dementia in Scotland magazine. If you have any questions or comments, get in touch with the Editor, Caroline Russell, by email: crussell@alzscot.org



Alzheimer Scotland, 160 Dundee Street, Edinburgh, EH11 1DQ

Designed by: Sara Johnston, Creative Designer

Phone: 0131 243 1453
Email: info@alzscot.org
Website: www.alzscot.org

X: @alzscot

Facebook: AlzheimerScotland

Instagram: Alzscot

LinkedIn: AlzheimerScotland



Alzheimer

Scotland

Local news Dementia in Scotland

© CSG CIC Glasgow Museums Collection

Special Riverside Museum display sparks memories

A new exhibit at Glasgow's Riverside Museum, harnessing the power of reminiscence therapy, was unveiled earlier this year. 'Car Sparks Memories' is a display designed for people living with dementia, their families, and carers. We know the benefits that reminiscence therapy such as Football Memories can bring, so we were delighted when museum curator, Neil Johnson-Symington, got in touch with lain Houston, Dementia Advisor, to ask if Alzheimer Scotland could help. As people who are living with dementia are often able to recall objects and events from many years ago, display designers were keen to speak to people with lived experience to seek their valuable input. A series of meetings with our Glasgow under-65s men's group followed and they were more than happy to get involved and share their thoughts and ideas. The display opened in August and

focuses on a previously donated vintage 1981 Talbot Avenger which had been brought out of storage and reunited with its owner, Angus Dougall. Angus has been diagnosed with dementia and seeing the car again had a profoundly positive impact.

The experience sparked interest among museum staff, and they began to explore the idea of creating a specialist exhibit with Angus' car as the centrepiece. The car - one of the last of its kind to be built in a Scottish factory now sits proudly in the Glasgow museum. Curated to evoke memories around life experiences and stories from the past focusing on the car's heyday of the 1980s - the display gives people the opportunity to talk about times gone by that hold special meaning.

lain Houston said.

"Riverside Museum is already a rich environment for reminiscing. We all know the pleasure of recounting happy times, but for people living with dementia, it can be harder to access those precious memories."



Judy Murray offers tennis tips for brain health to Dementia Café regulars

We were absolutely thrilled when tennis coach Judy Murray dropped into our Dementia Café at our Centre in Edinburgh earlier this year. Judy is backing an initiative that shows how beneficial tennis can be to help people keep their brains stimulated. Led by our team at Brain Health Scotland, the project promotes growing evidence that exercise is just one of many steps we can take throughout life that can help safeguard our brain health, and delay or even prevent the onset of some kinds of dementia. Brain Health Scotland was also the charity partner for the Brodies Tennis Invitational, which took place in Edinburgh in September.



During her visit, Judy very kindly passed on a host of tennis tips and tricks to regulars at the café. These can be practised anywhere, swapping a traditional hard ball for everyday items such as balloons, ribbons, and softer balls to make tennis more accessible. After her visit to the Dementia Café, Judy said:

"I've seen the many benefits that people of all ages and abilities can experience when they take part in physical activity.

"This has been the perfect way for me to support Brodies Tennis Invitational and its charity partner, Brain Health Scotland, and help make sure the event makes a positive impact in the community."

Issue 107 - Winter 2023 Local news

West Lothian couple's rugby rail adventure

Ailsa's husband, Richard, was diagnosed with Alzheimer's disease in 2019, aged 62. This autumn, they embarked on a European rail adventure to coincide with the Rugby World Cup.

"Richard has always been a huge rugby fan. I think it's the sense of community and camaraderie it brings. He has travelled the world in support of his beloved Scotland, visiting some beautiful, very far-flung places! "We managed to secure tickets to three of Scotland's games at this year's World Cup - Nice, Lille, and then the last one, against Ireland, in Paris. We applied through the cognitive disability ticketing process and thankfully, it worked out.

"Travelling is in Richard's blood; we've shared many special trips together — taking wonderful road trips across Europe. When we started discussing our options for the upcoming World Cup, we knew that Richard wouldn't be able to drive this time, so decided to take the train instead.

"We booked interrail tickets and planned a holiday to travel and sightsee between the three matches. Richard wants to be as independent as possible, for as long as possible and we think, while we can still have adventures, why not? This is an important message – a diagnosis of dementia doesn't need to spell the end of life as you know it. People with dementia



still have dreams, interests, and passions and we feel it's important to indulge those.

"Now we're home and delighted to say that Richard thoroughly embraced the trip. We enjoyed the Cote d'Azur, and loved visiting Venice for the first time. Then we headed back up through France to the games further north, stopping off at various places enroute – adding to our box of cherished memories. This trip was about defying dementia, making memories and showing others that it can be done."

Fife man completes once-in-a-lifetime challenge to honour late wife's love for dogs

Earlier this year, Dave Ramsay, 57, from Cupar in Fife embarked on a mission to raise funds for a Dementia Dog in memory of his late wife, Marcia, who was "dog daft". Marcia worked for Alzheimer Scotland and was passionate about the Dementia Dog project.

"Marcia was determined to help those living with dementia. When she learned about the Dementia Dog Project, it ticked every box. This collaboration between Alzheimer Scotland and Dogs for Good provides highly trained dogs to help families with a range of skills, from practical tasks such as fetching medication pouches to feeling socially reconnected into their community. She was a real advocate for the power of animal assisted therapy and this project filled her with joy."

Dave and biking companion Matt set out on their epic fundraising challenge – motorbiking more than 11,000 miles of the Trans Euro trail from Spain to Georgia. Spanning two-months, on a route filled with off-road tracks and high mountain passes, their YouTube channel 'Stinky Boots' soon established a keen following with

Boots soon established a keen following with people donating from around the world.

They successfully completed their trip, raising an incredible £22,000 which will fund a new dementia assistance dog in Scotland, to be named in Marcia's memory. Dave said:

"It really was the ride of our lives – full of challenges and ups and downs. But we kept going, full throttle, to raise money for this amazing cause."



6 Our support Dementia in Scotland

Meet Lori, our Young Onset Post Diagnostic Support Link Worker

Lori is one of Alzheimer Scotland's dedicated team of Post Diagnostic Support Link Workers. She joined us in January 2023 and focuses on helping people diagnosed earlier in life. We met up to have a chat about her role.





What made you want to embark on a career in post diagnostic support?

This is my first job since I graduated with a degree in Social Work last year. One of my study placements involved helping a gentleman aged under 65 who had recently been diagnosed with young onset dementia. We met regularly, and I felt privileged to play a part in helping him come to terms with his diagnosis. We formed a positive rapport, and I could see the constructive effect our meetings had. This experience inspired me to learn more about dementia, and the impact of being diagnosed at an earlier stage in life.



How would you describe the role of Young Onset Post Diagnostic Support Link Worker?

Varied! No two days are the same. The role focuses on providing a support mechanism to people who have received a dementia diagnosis, their families, and carers. This service is so important from a practical perspective – to help people understand more about the condition, manage symptoms, and provide information that will support with future planning and decision making. But the social aspect is vital too – being the link between people who are newly diagnosed and their peers is so important. Helping people maintain connections within their communities and meet others who share similar experiences can really give a boost to someone who might be feeling overwhelmed.

"Since receiving a
young onset Alzheimer's diagnosis
8 months ago, having Lori as my assigned
Post Diagnostic Support Link Worker has
been an invaluable source of support,
knowledge and comfort."

— Lynne (arroll



What does a typical day-in-the-life of Lori look like?

Each day can look very different. I cover Aberdeen city and all of Aberdeenshire, so I'm out and about a lot. Though I'm based in the Brain Health & Dementia Resource Centre in Aberdeen, I'm often on the road, meeting people in their homes or local centres that are convenient for them. We'll chat about things that are going well or figure out a solution if something is proving problematic. I'll suggest community based groups that might appeal and arrange participation if they are keen.

I'm in the Centre at least twice per week. I'll host one-to-one catch ups or gather groups together to enjoy some peer support – maybe a cuppa and a chat or an organised walk. These get-togethers are always positive, as people can ask questions, chat about their experiences, and just relax.

We also make use of technology to keep in touch, and over the last year, I've arranged online courses that are delivered in six-week blocks. These include general information sessions with guest speakers and virtual 'cuppas and chats' for people with dementia and their carers to get together, with me as facilitator.

Keeping on top of admin also takes up a portion of my day. I'll reply to emails and return any calls I have missed while on my travels. I also liaise with local mental health teams, GPs, and neurology consultants. This helps me to continually advance my learning and enhance my own practice.



What's the best thing about your job?

Without a doubt - getting to know people who have received a dementia diagnosis and their families. I've met some wonderful people and I always feel grateful that they allow me into their lives during what can be a very difficult time. I encourage people to continue to do at least one thing they really enjoy on a regular basis. Having hope is so important, and I try to convey this in the relationships I build.

Issue 107 - Winter 2023 Our support

Specialist Dementia Carer Link Worker

Working with North Lanarkshire Council, we have developed and introduced a new role of Specialist Dementia Carer Link Worker to provide expert support to carers of people with



dementia. The role will focus on meeting the needs, and improving the physical and mental wellbeing, of carers. The aim is to reduce stress and distress, maintain a healthy work/life balance and improve overall quality of life. There will be a Specialist Dementia Carer Link Worker in each of the six localities within North Lanarkshire.

Person-Centred Plans

A Person-Centred Plan is developed throughout the 12 months when a person with dementia is receiving post diagnostic support. The plan focuses on the life and wishes of the person, as well



as the things that are important to them. It can include life stories, hobbies, likes and dislikes, daily routines and future wishes. A group of our Post Diagnostic Support (PDS) Link Workers have been working on a Person-Centred Plan Toolkit that will help other PDS Link Workers when they are working with the people they support to create their plans.

"Our PDS Link Worker took notes about dad's life on every visit and a booklet was made. We have a lovely memory and dad loves to talk about it and show everyone." - Family member

Day care and day opportunity services for you

Alzheimer Scotland day care and day opportunity services are there for people of all ages living with dementia, as well as providing respite for carers. Health & Social Care Partnerships commission, that is, fund and contract Alzheimer Scotland and other providers to deliver these services. These types of support services are registered with the Care Inspectorate. For those who attend, however, it is often simply called 'Our Club', and they describe themselves as members of that club.

It is essential that everyone who attends feels valued, welcome, and relaxed. We start by getting to know everyone well by meeting them individually, to best understand them and what they wish to achieve by attending. We then provide the perfect environment to help people relax, increase social interaction and explore both new and existing interests. A person living with dementia, and carers can feel socially isolated. Our specially designed activities provide stimulation, engagement, companionship and enjoyment, which can have a hugely positive impact on quality of life, overall wellness and promote good brain health. This can help people to remain as independent as possible - a key aim of our services.

We offer a diverse range of activities and are always looking to enhance the variety of those available - this is very much led by everyone who attends



their Club. This can include indoor and outdoor sports e.g. golf, walking football, bowls, aerobics, tai chi, social outings, reminiscence, arts and crafts, music, games and quizzes, baking, and indoor and outdoor gardening. In 2023 we even grew our own potatoes and then cooked them for lunch! This type of support takes forward planning, and our experienced staff and volunteers support this process with each person. Alzheimer Scotland is commissioned to deliver these services in 17 locations across Scotland. If you want to find out more about them, you can email us at **info@alzscot.org**

"It has made a huge difference and built up my confidence again." - Attendee

"Mum thoroughly enjoys attending day care. The staff are simply wonderful. We feel very fortunate to have this. It provides us with much needed respite from caring for Mum, allowing myself and my brother to spend time together and it greatly reduces our stress levels." - Carer

8 Active Voice Dementia in Scotland

Spotlight on the National Dementia Carers Action Network



Alzheimer Scotland's Active Voice groups are at the heart of everything we do. Representing the voice of personal experience is a crucial part of our campaigning work and our two groups – the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) play a key role in that. Below we take a closer look at the work of NDCAN.

The National Dementia Carers
Action Network, or NDCAN
for short, is a member-led,
campaigning and awareness
raising group that works to
promote and support the rights
of those who care for people
living with dementia. Both current
and former carers of a person
with dementia in Scotland are
welcome to join.

Founded in 2011, they are the independent voice of carers within Alzheimer Scotland and provide a platform to empower those with experience of caring for someone with dementia to influence and inform policy and practice. NDCAN has equality, diversity, inclusion, and human rights at its heart, and its members bring a wide range of personal experience, valuable knowledge and skills to the group.

"To anyone thinking of joining and feeling nervous, I would encourage you to join. You gain so much, and I feel it helps me emotionally as I am able to make a difference. I can't help Mum, but I can help make the future better for others."

- Elaine Deehan, ND(AN

Group members meet regularly with Scottish Government Ministers and only last month met with the Minister for Social Care, Mental Wellbeing and Sport to raise concerns about the gap between dementia policy and implementation, and to make the case for a greater focus on dementia and brain health in the Scottish Government's Women's Health Plan. They also engage with MSPs to highlight current issues and help shape ideas, such as recent proposals for a commissioner for older people in Scotland.

NDCAN members ensure the voices of dementia carers across Scotland are heard by the government in their consultations. They input into National Dementia Strategies and are currently engaged in helping to develop delivery plans for the most recent strategy. Members also share their personal experiences, speaking at national and international conferences and events - this year alone they've spoken at events from the 'Let's Talk About Dementia' conference in February to Alzheimer Scotland's Annual Conference in September, and Alzheimer Europe's Conference in Helsinki in October.

ndcan
National Dementia Carers
Action Network

"Being an ND(AN member has been one of the most galvanizing things in my life. Alzheimer Scotland promises 'action on dementia'. I am eager to be part of that."

- Thea Laurie, ND(AN

NDCAN members have helped to train workforces by sharing their experiences with health and social care professionals, this includes the Dementia Champions Programme. They also developed a series of nine support booklets 'For Carers, By Carers'.

If this sounds like something you'd like to be part of, NDCAN would love to hear from you. From attending meetings, supporting research, participating in consultations, and sharing your experience of caring for a loved one with dementia – there's so many ways in which you can make a difference.

If you'd like to learn more, get in touch by emailing us at activevoice@alzscot.org or visit www.alzscot.org/ndcan

Issue 107 - Winter 2023 Active Voice

Active Voice at Alzheimer Europe

Conference

Between 16-18 October, our Active Voice team flew the flag for Alzheimer Scotland at the 33rd annual Alzheimer Europe conference in Helsinki. Joining a delegate list of over 1000 people from 48 countries, three SDWG members and three NDCAN representatives flew out to Finland. Under the banner, 'New Opportunities in Dementia Care, Policy and Research', the members made sure the voices of people with personal experience were heard loud and clear.

The conference enabled our members to discuss their contributions to the Scottish Government's fourth National Dementia Strategy. NDCAN's Elaine Deehan, Barry Northedge, and Anne Tierney presented a powerful recount of the group's engagement with 127 people with dementia and 171 carers to inform the content of our response to the consultation.

The voices of people living with dementia were front and centre throughout, with SDWG's Margaret McCallion treating the audience to an excerpt from the academic textbook, 'Occupational Therapy and Dementia'. With the opening chapter written by members of SDWG, it was fitting that Margaret was able to share her writing, highlighting the importance of creative activities to help people with dementia live well.

Delegates heard from SDWG member Stuart Dougall about his contribution to an animation working group. The group



researched the role animation can play as a digital solution for sharing rehabilitation advice. As well as outlining the animations that have been tested so far, Stuart shared his own story which has now been made into a short animation.

The conference also allowed SDWG and NDCAN to showcase a poster presentation depicting their 'Active Voice Toolkit' created in response to feedback from frontline staff who hear from people every day about what's important to them, what's working well, and what's problematic in their lives. This generated a lot of interest from delegates keen to hear more about the Toolkit's resources. Beyond the conference sessions. members embraced networking opportunities, renewing past acquaintances while making new connections, sharing ideas, and discussing future projects. Members are already looking forward to next year's conference which will be held in Geneva, Switzerland in October

2024

"It is important that we engage with, and hear, the voices of people with dementia..."

Muistiliitte

33rd Alzheimer Europe Conference

Helsinki / 16-18 October 2023

The Scottish Dementia Working Group (SDWG) is a national, member-led, independent campaigning and awareness raising group for people who are living with a diagnosis of dementia in Scotland. We are supported by Alzheimer Scotland's Active Voice Team who ensure that the opinions of those with personal experience are heard. Membership is free and open to anyone who has dementia in Scotland. Our only requirement is that you would like to meet other people with dementia to discuss things that really matter to you. Although we are not a support group, members say they have gained friendship and reassurance from coming together with others who have shared experiences. The more SDWG members we have, the louder the voice of people with dementia in Scotland will become. If you're keen to join us, you can email us at activevoice@alzscot.org or visit www.alzscot.org/sdwg

Together we're the change – are you in?

Our 2023 Winter Fundraising Appeal

This year, our winter campaign focuses on research and some of the wonderful people we support and work with who give their time to dementia research. In our 'We're All In' campaign, we celebrate the idea that each of us, in our own unique way, can contribute to dementia research. When you think about research, you might think it's just about white lab coats and test tubes. Dementia research can take many forms though - it can be about completing surveys and joining focus groups as well. You don't have to have a diagnosis of dementia either, anyone can participate. We brought three people with dementia together to take part in our campaign film. Willy Gilder, Kenny Moffat and Rynagh Flynn all live with a dementia diagnosis, and all give their time to dementia research.

Our campaign strapline Together we're the change – are you in?' sums up perfectly how working together today can bring hope for tomorrow.

"Being involved in research at every stage gives me a focus and

Kenny

a feeling of worth and makes me feel I'm contributing something for others coming behind me." - Kenny

"Research is one way for me to find out progress, find out more about what's being done, what's out there and to meet other people." - Rynagh

How you can get involved:



Participate in research



Donate to research



Learn about research

Our film also features Neuroscientist and Alzheimer Scotland Ambassador, Professor Tara Spires-Jones. Tara is based at the Centre for Discovery Brain Sciences at Edinburgh University. We were lucky enough to be able to visit Tara with a film crew at the Centre and chat to her about her work and why it's so important for people to get involved in dementia research.



"Right now, we are working hard to make the lives of people with dementia better *now*, and in the future I think we are going to find ways of completely preventing or hopefully even reversing the symptoms of dementia." - Professor Tara Spires-Jones

Issue 107 - Winter 2023 Winter campaign 11

"Traditionally, people with dementia have been written off. There's always been a focus on the 'end-stage'. But there are thousands of people who are living with the early stages of the condition – and they have valuable contributions to make."

- Willy

Why does dementia research need your support?

For every £10 pounds of health and social care costs associated with dementia, just 8p goes towards dementia research.

Could you be the change?

Every penny counts when it comes to supporting dementia research. Your gift will help to improve the quality of life for people now and work towards a future without dementia. If you are able to, please donate to Alzheimer Scotland this winter.



What your contribution could support:

£10

could help a carer to take part in an online research session and have their voice heard

£30

could fund a person to travel back and forth to a hospital to take part in clinical research

£50

could support a researcher to conduct a focus group

£100

could fund Scotland's only dementia brain tissue bank for a day

Join Dementia Research (JDR)

JDR is a nationwide online and telephone service that makes it easier for people to register their interest in volunteering for dementia research studies. Anyone, with or without dementia, can register as a volunteer. The service was launched eight years ago by the National Institute for Health Research (NIHR) in partnership with Alzheimer Scotland, Alzheimer's Research UK and the Alzheimer's Society. You can find out more on their website

www.joindementiaresearch.nihr.ac.uk/

Join dementia research



You can watch our film and find out more about our campaign here.

Fair Dementia Care update

Alzheimer Scotland's Fair Dementia Care Campaign continues to challenge the unfair charges faced by people living with dementia with complex physical and psychological symptoms which require specialist health and nursing care. People with advanced dementia living in Scotland's care homes do not have equality of access to the health care they need. Fair Dementia Care is about ensuring that those with advanced dementia receive free health and nursing care on a par with those with other progressive and terminal illness. In June 2022. we wrote to Scottish Government Ministers clarifying our position and explaining that we believe that when a person with dementia progresses to the advanced dementia stage, they should be offered access to an appropriate assessment process that will determine if their needs are primarily health care needs and if so, should be free.

At present there is no mechanism for this, however we believe this is wrong and we provided a legal opinion that there is a duty on the NHS to provide this assessment and if an individual's needs are deemed to be primarily health care, then the NHS should fund this - not the person. After some ongoing discussions and communication, Scottish Government legal officials have recently agreed in principle to

dementia are facing

in care costs every year

This needs to change.

both legal teams, Alzheimer Scotland and relevant government officials. We will keep you updated on the progress of this.



Long Term Care Commission update

Alzheimer Scotland's Long Term Care Commission was established to consider alternative approaches to delivering more effective methods of long term care and support. The Commission, led by former First Minister of Scotland Henry McLeish. will explore what changes and improvements are needed in the current environment and identify innovative, cost-effective, and affordable solutions for achieving any recommended changes. Members from both the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) are part of the Commission, adding the valuable voice of personal experience.

The Commission will also hear from a number of key stakeholders as it works to create a set of national recommendations for Scottish Government

and other stakeholders. These recommendations will set out a new, fairer, more person-centred and sustainable policy, practice, and funding model for the long term care of older people and people with dementia in Scotland.



The Commission will report

its findings in

spring/summer

2024

Issue 107 - Winter 2023 Events 13

Alzheimer Scotland's Annual Conference 2023

It was wonderful to have over 350 attendees join us at our Annual Conference at the Edinburgh International Conference Centre (EICC) in September. This year's theme was 'Influencing positive change & progressive practice in dementia' and our speakers during our three conference sessions – 'Implementing change to improve lives', 'Women's brain health & dementia' and 'Looking to a brighter future' gave informative and inspiring presentations on a range of topics.

As always, people with personal experience were at the heart of the event with members from the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) welcoming everyone to the conference and also introducing each of our three sessions. The Every Voice Community Choir joined us during the lunch break and performed a selection of songs for attendees.

If you were unable to attend this year's conference, the videos from the day which contain all presentations are still available to watch on our website.

www.alzscot.org/conference23



Supporter 'Thank You' Event

Our most recent Supporter Thank You event was held at our Centre in Oxford Street in November. The event was a great opportunity to meet in person some of our wonderful fundraisers who live within the local Glasgow area, and thank them for their dedication and passion for helping us make sure nobody faces dementia alone. We look forward to hosting more of these events throughout Scotland over the coming year, so we can continue to thank even more of our generous supporters.



Virtual reality – where anything is 'virtually' possible

Our Innovation and Development team has been working with people with dementia to explore the benefits of virtual reality (VR) and how it can improve health and wellbeing. Thanks to Scottish Government funding, we were able to buy Meta Quest 2 headsets for all our Centres across Scotland. We have also trained 35 staff members to become Digital & VR Champions, allowing them to offer VR experiences to community groups.

As co-design with people with personal experience is at the heart of everything we do, Martin, one of our VR trail blazers, who is living with dementia and frequently uses VR to self-manage his symptoms, created a Top Tips guide for facilitators and users.

Martin's Top Tips for Users

- Don't be afraid to try it
- Take your time within the headset and allow yourself to adjust
- Practise getting to know the buttons on the controllers
- Spend no more than 15-20 minutes in the virtual environment (use a timer as you can lose track of time)
- If you know you get motion sickness, it might be good to sit down while using the headset

The feedback from case studies has shown a 100% improvement in mood either from neutral to energetic or from sad to neutral. In 75% of cases, users reported an improvement in anxiety level from mild-moderate to none.

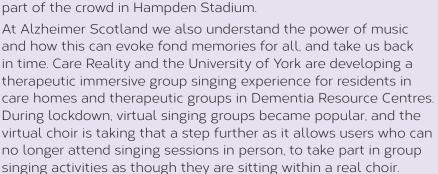
Gordon

Gordon became interested in seeing if the VR systems could have a positive effect on his sleep after experiencing physically acting out his dreams as a result of his diagnosis of Lewy body dementia. Gordon's dreams have previously been impacted by something he has watched on television before bed. Gordon and his wife Anne are excited to see if, through time on the VR watching a calming video, it can have a positive effect on his REM sleep.

Ann

Ann has a form of young onset dementia called primary progressive aphasia. She loves to keep active but sometimes feels limited by her condition. Using VR has allowed Ann to try things that she had only ever dreamed of doing- like flying over a glacier in Norway! And experiencing rock climbing in VR has inspired Ann to think about giving it a go in real life.

We are also working with external colleagues who are developing reminiscence and theraupetic virtual experiences, including a partnership with the Scottish Football Museum, Abertay University and Crab.bit to create 3 short reminiscence experiences. These are – attending a football game in days gone by, travelling on the bus to the game, going through the turnstile and being part of the crowd in Hampden Stadiur



Virtual reality can open up a new or previously experienced world to all, ensuring that virtually – anything is possible.



Opening of new Brain Health Service and Clinic

A new Brain Health Service and Clinic located in our Aberdeen Brain Health & Dementia Resource Centre was launched earlier this month. This is a multi-agency project between Scottish Government, NHS Grampian and Alzheimer Scotland which includes our Brain Health Scotland team.

What is a Brain Health Service?

We now know that many of the diseases that can cause dementia start in the brain a long time before obvious symptoms might begin to show. Our Brain Health Service in Aberdeen will enable people to understand and identify their own personal risk for the diseases that can lead to dementia. There are many things people can do to protect the health of their brain throughout life and help reduce the risk of developing certain brain diseases. This service supports people to reduce their risk by providing personalised advice to support lifestyle changes.

The service is available for anyone, regardless of age, who might have concerns about their memory or brain health. It is also for anyone who wants to find out more about reducing their risk of developing dementia in the future.

You do not need an appointment for the Brain Health Service which is available at our Brain Health and Dementia Resource Centre, 13-19 King Street, Aberdeen, AB24 5AA.
Open Monday - Friday, 9.00am - 5.00pm.

And if you are a resident in the NHS Grampian region you can contact the NHS Grampian Healthpoint on 08085 202030



Brain Health Clinic

The new Brain Health Clinic offers people the opportunity to understand more about their future risk of dementia and put in place a plan to help reduce that risk. Referrals to the Brain Health Clinic can come from GPs, an NHS Grampian Healthpoint Advisor or the Centre Manager at the Alzheimer Scotland Centre.

The clinic is delivered by NHS Grampian staff – a Clinical Nurse Specialist for Brain Health and a Consultant Psychiatrist. At the clinic, people will be asked to complete a lifestyle questionnaire. They may also be asked to do memory and thinking tests, have their height, weight and blood pressure measured and may also have a blood sample taken.

Everyone who attends the Brain Health Clinic is provided with a personal action plan. This helps with taking positive steps for brain health and reducing the risk of diseases that can lead to dementia. People visiting the clinic will be invited to register with Join Dementia Research (JDR) and the Neuroprogressive and Dementia Network to participate in research studies.









You can find out more about the different steps you can take to protect your brain health and even build your own personal Brain Health Plan on our Brain Health Scotland website www.brainhealth.scot 16 Your support Dementia in Scotland

Grandson treks 230 miles from Scotland to Ireland, retracing Grandad's 1947 journey

Michael's Grandad lived with vascular dementia for over seven years, sadly passing away in February. Following his death, Michael decided to retrace the steps his Grandad took as a young man, when he emigrated from Raphoe in County Donegal to Cardenden in Fife. A staggering 230 miles and 500,000 steps later, Michael explains:

"My Grandad was born and raised in Raphoe. In 1947, at the age of 19, work brought him to Scotland. Here, he married my Gran, and they lived in Cardenden for 73 years. But he was proud of his heritage, holidaying in Ireland often. His last remaining sibling, Eunan, still lives in the family home back in his hometown.

"Grandad was a keen walker, an activity we always enjoyed together. So, when thinking about fundraising for Alzheimer Scotland, I knew a sponsored walk would be fitting. Despite the daunting distance, I decided to walk 'home' for Grandad, from the house he shared with my Gran, to his childhood town, and then on to meet his brother in Donegal. Crossing the Forth Road Bridge was just the beginning of my epic challenge; walking across the country through Newmains and onto Ayr, where I took the coastal path down to Cairnryan for the ferry to Belfast. Once there, I walked through Antrim, onto Strabane, and then across the border into Raphoe.

"I was greeted by a lone piper who escorted me to Eunan, at his front door. I presented him with a Hamilton clan tartan scarf which had belonged to my Grandad, along with a tie pin featuring the Scottish and Irish flags. Arriving there was a really humbling, emotional experience. Every one of the half a million steps I took was for my Grandad, and the over £4000 I have now raised is for Alzheimer Scotland, in his honour."

Michael's trek raised a fantastic £4,600 for Alzheimer Scotland. He spoke about his experiences and why he wanted to raise funds at our 'Thank You' event for supporters in Dundee in September.

Scotland's Memory Walk 2023

A huge thank you to everyone who took part in Scotland's Memory Walk this year. From Stornoway to Kelso, it was fantastic to see so many people put on their purple t-shirts and walk for someone they love. 'Your walk, Your way' meant that people could walk wherever they wanted, whether that was somewhere that held special memories or just a chance to think in their local park.



Issue 107 - Winter 2023 Your support 17

Creative dementia campaigner uses her skills to raise funds and awareness

Lois Wolffe's mum, an artist, was diagnosed with dementia in 2021. Inspired by her creative flair, Lois began embroidering details of her mum's life on a fisherman's smock to encourage more confident conversations about the condition.

"When Mum was diagnosed with complex mixed dementia she said, "I only have a little bit of Alzheimer's, don't I?" and I replied, "It's just a label, Mum...we'll always take care of you". She never referred to it again.

"Back in the 50s, Mum was an art student, painting and drawing whatever was in front of her. One day, I found an old fisherman's smock in the back of a cupboard and asked if I could embroider it – she'd worn them for years over her clothes whenever she sculpted or did pottery.

"And so, my smock project was born, as I began stitching

themes from Mum's life onto the

cloth. Scottish born, she'd moved between here and South Africa many times, so I started by stitching the swallows she could see through her window. We reminisced and shared stories, and with every stitch, I felt like I was sewing love into the fabric. Mum now lives happily in a care home. I continue with my smock project, hoping that it encourages people to talk more openly about dementia."

The inspirational Lois was nominated for Creative Fundraiser of the year 2023 in the GoCardless JustGiving Awards. Currently, Lois has raised over £1,300 for Alzheimer Scotland.





Alzheimer Scotland's Student Research Programme

In autumn 2022, Alzheimer Scotland launched a new Student Research Programme. The programme, which is supported by the Scottish Dementia Research Consortium (SDRC), funds studentships for projects on dementia and brain health in Scotland. The programme offers much more than the funding. It provides the opportunity for students to pursue a career in dementia research, with successful applicants having the chance to develop their research communication skills, work with people with personal experience as well as other valuable networking opportunities.

A programme panel which includes members of the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) selected the theme for 2023 which was 'diagnosis' and the programme's first grant was awarded to the University of West of Scotland. An MRes student was appointed in autumn 2023.

The panel is currently in the process of selecting a theme for our next MRes 2024 round, and we are now inviting proposals from academic institutions within the SDRC membership network.

Find out more at www.sdrc.scot





National Dementia Advisor Service

On World Alzheimer's Day, Thursday 21 September 2023, we officially launched our new National Dementia Advisor Service. The service, which is completely funded by Alzheimer Scotland from donations and fundraised income, provides a responsive, high quality information, advice and advocacy service relating to all aspects of brain health and dementia. Our National Dementia Advisor Service complements our existing National Support Services such as our 24 hour Freephone Dementia Helpline and our National Counselling Service.



Call us on: 0300 373 5774

(Charged at a local call rate)

Lines open: Monday - Friday, 9am - 5pm



Email us at:

NDAS@alzscot.org



You can find further information about the service on our dedicated web page www.alzscot.org/ndas



We are recruiting new volunteers to be part of our Dementia Helpline team

Can you spare 8 hours each month to help us make sure nobody faces dementia alone?

Join us for an Alzheimer Scotland & 24 hour Dementia Helpline online information session on Thursday 18 January from 6pm until 8pm.

Our next Helpline Volunteer Preparation Programme is running in Glasgow on Saturday 27 and Sunday 28 January 2024.

For further information and other training dates please email helpline@alzscot.org

www.alzscot.org/helplinevolunteer

Dementia

Alzheimer
Scotland
Action on Dementia

Helpline
Freephone 0808 808 3000
Email helpline@alzscot.org

Alzheimer Scotland - Action on Dementia is a company limited by guarantee, registered i Scotland 149069 Recognised as a charity by the Office of the Scotlish Charity Regulator, no SC022315 160 Dundee Street, Edinburgh, EHII 100, 0131 243 1453, www.alzscot.org



Alzheimer







Join TeamAlzScot! Spring 2024

Spring into action this new year by taking on a run, walk or abseil for Alzheimer Scotland!

Inverness Half Marathon / 5k
10 March | Inverness

Falkirk Wheel Abseil
15 March | Falkirk

Supernova 5k (run in the dark)
15 & 16 March | Falkirk

Kilomathon 13.1k, 6.5k, 2.62k 5 April | Edinburgh

Glasgow Kiltwalk 28 April | Glasgow



