

Dementia in Scotland



Winter 2021 – Issue 103

“
The little moments
of *magic* make
such a difference
”



Winter Edition

– packed with moments of *magic* from across Alzheimer Scotland



We're here for you this winter and always.

We know how stressful and disorientating the festive holidays can be for many people living with dementia and their families and carers, with disruption to daily routines and difficulties accessing support, services and assessments for those who require it.

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



Our 24 hour Freephone Dementia 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. You can also contact our Helpline team via email on helpline@alzscot.org



Our local staff teams are here for you too. If you are not already connected to your local Dementia Resource Centre, call our Helpline number and we will share the name and contact details of your local Dementia Advisor.



If you have a family member living in a care home in Scotland, and need some support or advice with access to visits, our Action on Rights team are here to help. You can reach them by either calling our Helpline number, or by emailing the team directly on actiononrights@alzscot.org

If you have to leave your details on our answering machine, please be assured it will get picked up and someone will be in touch as soon as possible.

24 HOUR

**Alzheimer
Scotland**
Action on Dementia

**Dementia
Helpline**

Freephone 0808 808 3000
Email helpline@alzscot.org

Making sure nobody faces dementia alone.

Contents

4 – Local news	12 – Our support	22 – Digital updates
8 – Campaigning for change	14 – Winter fundraising appeal	24 – Celebrating NDCAN
10 – Events	16 – Your support	25 – Brain health

Welcome

Welcome to the winter edition of Dementia in Scotland magazine. I would like to first of all acknowledge the significant and unimaginable stress, the pain, the loss and the grief that so many people living with dementia, and their families and carers, have gone through during this pandemic. The hidden impact and, indeed, the burden and the cost of the pandemic on our community is simply unimaginable. Our frontline staff and volunteers have worked tirelessly to ensure we remained there for the people we support throughout this challenging year, developing new ways of working and opening our doors again. You can find out more about some of these developments in this edition, including both the Outdoor and Virtual Resource Centres, and the remobilisation of our services.

We know how difficult the winter months are for the people we support. You'll see to the left of this page an overview of the key ways in which Alzheimer Scotland can offer support over this period. We want to reassure you that we are here for you this winter.

The theme of our Annual Conference this year was 'moving forward together', where we highlighted the need for a clear rights-based vision for transformation. We also emphasised the need to finish what's been started and deliver on the long-standing commitments from several national dementia strategies. We must develop a level and

depth of consistent practice, care and support of the same quality every time for every person everywhere throughout Scotland. That's why we need a national vision for transformation, and you can read our Campaigning for change update on page 8, including news on our Fair Dementia Care campaign.

We simply could not provide the level of support we do without such a dedicated army of fundraisers and supporters. I am continuously humbled by the myriad of ways people raise vital funds for Alzheimer Scotland. From our frontline staff and volunteers, to our thousands of supporters – thank you to each and every person who makes it possible for us to support people with dementia and their families and carers.



Henry Simmons

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



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Outdoor Dementia Resource Centre



By Gillian Councill, Localities Lead, Alzheimer Scotland

Freedom is something we all desire as human beings. Sometimes when we love someone and seek the best for them, we inadvertently make decisions for people and create environments that fail to identify people's need to feel free. As I sit looking out of my home office window, I am inspired by the golden light and the miraculous colours of autumn trees, shades that only nature can create. Some days the office environment can feel confining, but I am fortunate enough to know that I can walk and run and explore the natural environment when I need to.

People living with dementia don't always have the luxury of enjoying nature in the same way, to absorb the sounds and scents that an indoor environment can't replicate.

In an effort to make the natural environment more accessible, Alzheimer Scotland is developing the country's first Outdoor Resource Centre - specifically designed to support people living with dementia, their carers and families. This will enable people to enjoy and explore the outdoor environment. Based at Badaguish Outdoor Centre, Aviemore, we will be offering a programme of outdoor based therapeutic

activities. We have secured 7 year project funding to create this, and will receive almost £900,000 in start-up funding through the Heritage Lottery Fund in partnership with Cairngorm National Park Authority. The bid includes a team who will run the therapeutic programme, which is centred in, and inspired by, the natural environment. We will occupy a space on the site of Badaguish, including refurbishment and upgrade to make the wooden cabin style building dementia friendly.

The project plan will involve a John Muir Award specifically developed for people with dementia. The John Muir Award is an environmental award scheme which encourages people of all backgrounds to connect with, enjoy and care for wild places. The creation of this will allow people to achieve and learn new skills when they are with us, incorporating environmental appreciation and learning. We are part of the NHS Green Health Prescribing initiative and our vision is that we will work towards a clear referral process whereby

people with dementia can benefit not only from our services but from the wider range of opportunities within the initiative.

We recognise that we are fortunate enough to live in the Highlands and although much of this project will benefit those living in the Cairngorm National Park area, the John Muir Award that we are developing will be available to people across Scotland. The aspiration is that people with an outdoor space to explore will have the opportunity to take part in and be supported to achieve the award. By exploring and understanding more about the natural environment in a way that is sociable and inclusive, we'll strive to help people feel like they are part of something.

It is unusual to hear about funding initiatives like this being directed towards the older generation, and even less so to people living with dementia. This funding will give us the opportunity to reimagine the environment of care and how we perceive dementia.



For more information, please contact Gillian Councill at gcouncill@alzscot.org

Virtual visits to the V&A

By Nikki Lorimer, Localities Lead, Alzheimer Scotland

Since the opening of the museum in September 2018, Alzheimer Scotland and V&A Dundee have worked together on several ways to bring creativity and culture to those living with dementia in the local area, delivering tours of the major exhibitions and workshops in Alzheimer Scotland's day care and Dementia Resource Centres. We explored ways of continuing this high-quality support during the pandemic and gave live virtual tours which included the Mary Quant exhibition and the Scottish Design Galleries, allowing many people to take part, regardless of their physical location or ability to travel to the museum. This reduced people's isolation and ensured they felt connected.

Alzheimer Scotland and V&A Dundee were able to take the joy and inspiration of design to people living with dementia and their carers. Digital technology enabled rich conversations while stimulating the mind and senses and provided opportunities for people to socialise, share memories, discuss, laugh, and contemplate.

Following the success of the virtual tours we developed a programme of online activities to bring the Mary Quant exhibition to life. The activities explored all aspects of the exhibition through presentations, a virtual walkthrough, handling tactile objects and group discussion. Handling materials were created and shared to participants, who then had a tactile experience of the exhibition in their own homes.



We wanted to experiment with how a hybrid way of working could be delivered at scale, combining the benefits of digital content reaching a greater number of people, with the friendliness of an in-person event. Our newly launched Virtual Resource Centre provided an opportunity and V&A Dundee was delighted to pilot a tour of their exhibition, 'Night Fever: Designing Club Culture' in June 2021, during Dementia Awareness Week.

This was a new way of working for both Alzheimer Scotland and the museum, being the very first in-person tour also broadcast live to audiences online. It was a huge success, nearly 100 people watched online, enjoying the same experience as those in the galleries.

The feedback from our work so far has been overwhelming, highlighting how a hybrid way of working and a connection with culture can support and enhance the lives of those living with dementia, as well as their carers. People have said they felt connected, stimulated and joyful. At a time when access to services can be reduced, and the prospect of doing things that were normal before the pandemic feel like a distant memory, having the ability to work together on delivering meaningful shared experiences is incredibly powerful. The joy of culture and human connection is more important than ever – and we can still stay connected and enrich each other's lives, even when we can't always be together.

Our collaboration with the V&A Dundee has been a positive experience, and it is something we want to continue and build on using a blended approach.



Opening our doors again

By Nikki Lorimer, Localities Lead, Alzheimer Scotland

Like so many other services, Alzheimer Scotland had to close our physical doors when the country went into lockdown in March 2020. We were committed to continuing our support and we quickly put in place a range of online groups, wellbeing calls, and other forms of support such as a volunteer befriending project supporting people in therapeutic activity in their own homes. This made sure they remained connected with, and supported by, Alzheimer Scotland.

When restrictions started to lift, and following Scottish Government guidance, we began to shape a plan for opening our doors again. We looked at the layout and space in our Resource Centres and given the need for social distancing, we agreed our services would be delivered in a different way. This meant shorter sessions for smaller numbers of people while supporting as many people as possible over more days. As a result of our frontline staff having such warm and positive relationships with the people we support, we knew where there were shared interests or existing friendships and used this to form smaller 'bubbles'. It was very difficult during this planning process to know that some people who had previously attended our Centres would be unable to return to them. The pandemic has had a devastating impact on the dementia community, with many people



moving into long term care, having increased needs, or some having sadly died.

People with dementia and their carers were front and centre of our reopening plans, we engaged with them and discussed our vision for the remodelled Day Care. It was clearly important that people felt comfortable returning to a different set up, so in order to build confidence and offer reassurance, we:

- developed walkthrough videos of the building, highlighting the differences and what we were doing to keep people with dementia and staff safe.
- explained we would be wearing masks, would take everyone's temperature on arrival and ask them to sanitise their hands.
- showed how we had reorganised the Dementia Resource Centres and that furniture was arranged to support physical distancing.

People made their own decisions on returning to the service, and if they felt they were not ready to return, we reviewed this with them on an ongoing basis.

We have always prided ourselves on the homely look and feel of our Centres, so the process of decluttering was difficult for our staff as it felt impersonal. The big smiles on the faces of the people attending is a wonderful reminder that it's not soft furnishings which make our services so invaluable, it's simply the connection with others.

Archie Noone

By Jim Pearson, Director of Policy & Practice, Alzheimer Scotland

Archie Noone, a valued colleague and friend of Alzheimer Scotland, sadly passed away in October this year. Archie was a member of our Board of Trustees, Vice Convener of Alzheimer Scotland, and former Chair of the Scottish Dementia Working Group (SDWG).

In July, Archie was awarded a Lifetime Achievement Award at the National Dementia Awards for his campaigning work. He accepted this award with great pride and valued the well-deserved recognition, and we featured his award ceremony at our Annual Conference in September.

Over the years, Archie campaigned passionately to improve the lives of people with dementia, raise awareness and challenge perceptions about dementia. Archie was a wonderful ambassador for both Alzheimer Scotland and the Scottish Dementia Working Group.

Archie was dedicated to his campaigning work, travelling from his home in Dundee across Scotland on a weekly, if not daily basis for meetings and events. He went to conferences in The Hague and even as far as Chicago to share his lived experience and to campaign for change. He often wore the Alzheimer Scotland tartan at these events, and we were proud to have him represent us.



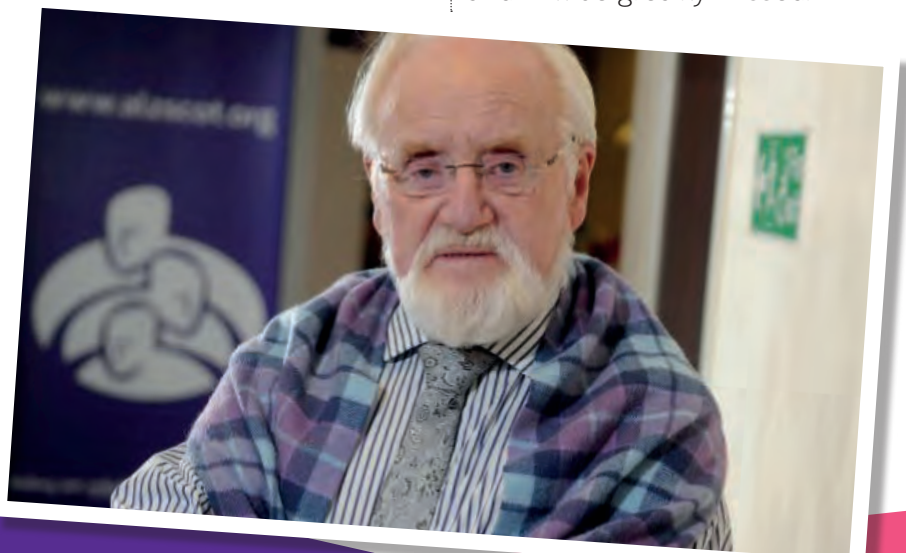
Archie was interested in everything, he supported and was involved in dementia research, sitting on research advisory groups, and working closely with our colleagues at the Alzheimer Scotland Centre for Policy and Practice. He was a strong advocate for, and heavily involved with, the Care Inspectorate, as well as acting as an expert advisor to NHS Education for Scotland, the Social Services Council, and the Promoting Excellence team. Making sure the voice of someone living with dementia was being heard by those making policy decisions was at the heart of everything he did.



Pictured above with our colleague Wendy Rankin, who Archie held in highest regard.

Archie was a positive influence to so many people over many years, he always welcomed new members in to the Scottish Dementia Working Group and helped them feel at home. His fellow group members have spoken so highly of him and have expressed their sadness at the loss of a good friend.

Archie lived with dementia, but like other members of the Scottish Dementia Working Group he gave the precious commodity of his time to campaign to change the lives of people with dementia who came after him and was truly deserving of the Lifetime Achievement Award. Archie has left a mark on many of our lives and will be greatly missed.



Campaigning for change – an update

By Jim Pearson, Director of Policy & Practice, Alzheimer Scotland

Throughout the pandemic, Alzheimer Scotland has campaigned in order to ensure that the hidden impact on people with dementia and their families and carers was understood and acted on. We also continued to campaign for the transformation of Scotland's health and social care system to ensure world leading care, support and treatment for every person with dementia, and those who care for them, beyond the pandemic.

Fragmented policy implementation

Scotland is internationally recognised as having some of the most progressive national dementia policies in the world. However, despite the commitment in some areas to delivering on this, many people with dementia and their families experience a fragmented local situation. This is why Alzheimer Scotland have called upon the Scottish Government to adopt and implement our vision for transformation and 7 key recommendations (see opposite page).

Additional funding for Post Diagnostic Support

We are pleased that some progress has been made. For example, the Scottish Government has committed £3.5m of additional national funding to ensure local areas have the capacity to offer every person who is diagnosed with dementia the critical support they need and deserve. This is the first meaningful national dedicated budget for post diagnostic support and will provide local areas with a substantial investment to help tackle this fragmentation and postcode lottery. We are also pleased that the Scottish Government supported the development of our Action on Rights team and our National Counselling Service – both vital forms of support for people during the pandemic. You can find out more information on page 12.

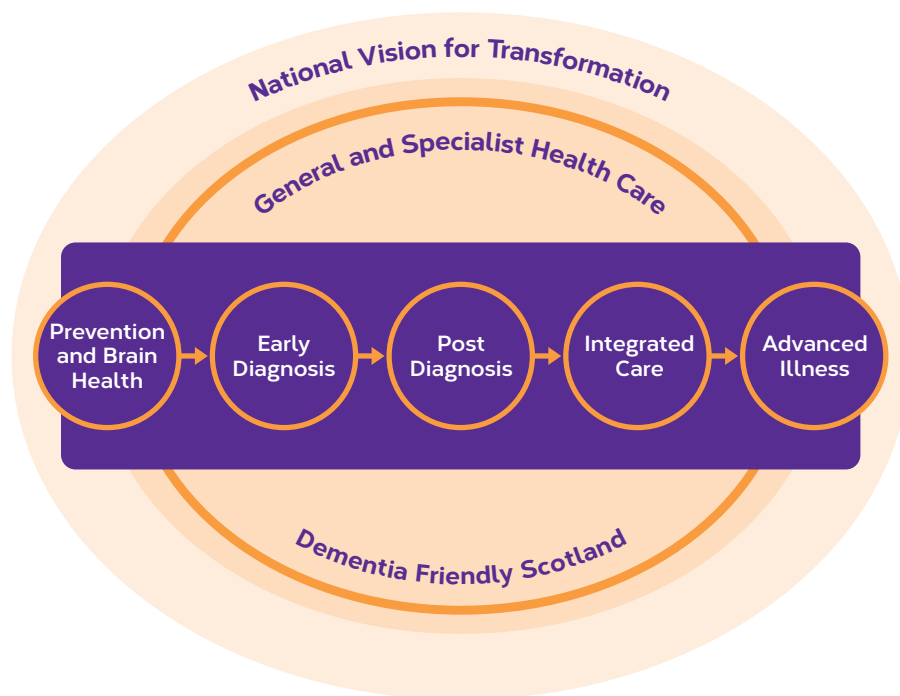
National Care Service

We fully support the Scottish Government's commitment to establish a National Care Service and we have fully engaged in their consultation on this. However, people with dementia, their families and carers have no time to wait and we need further investment and change now in line with our key recommendations.



At our recent Annual Conference, Alzheimer Scotland Chief Executive Henry Simmons outlined what our vision for transformation is, and our key recommendations.

Alzheimer Scotland is asking the Scottish Government to commit fully to this shared national vision of transformation and deliver the following key recommendations:



1

Establish a dedicated Dementia Directorate with an agreed national vision & 7 key areas of system transformation and redesign



2

Continued investment in brain health and prevention



3

Increase funding and guaranteed access to Post Diagnostic Link Workers



4

Develop and introduce the role of Dementia Practice Coordinators



5

Develop advanced care and specialist teams



6

Develop a new model of innovative specialist dementia units



7

Continue to deliver Promoting Excellence, extend Dementia Champions and sustain Nurse & Allied Health Professional Consultants



This model of transformation and the accompanying recommendations provide the foundations for progress in delivering on the commitments and priorities of each of our previous national dementia strategies, as well as providing a blueprint for a way forward in advance of the National Care Service.

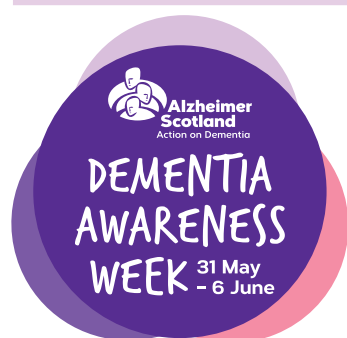
Fair Dementia Care

Transforming our health and social care system might take time to deliver, however, ending the inequality of those living with advanced dementia whose needs are unequivocally health care needs, and who have to pay for their care, could stop now. That is why we have yet again called on the support of former First Minister, Henry McLeish, to act as an Ambassador for Alzheimer Scotland and help us bring an end to this unfair and unequal treatment.

If you are a person with dementia, or a family member or carer, and interested in supporting any of our campaigning work, we'd like to hear from you. Please contact info@alzscot.org

Highlights from Dementia Awareness Week and our Annual Conference

By Marri Welsh, Executive Lead, Communications & Campaigns, Alzheimer Scotland



*Hidden voices,
Hidden impact,
Hidden cost:
Let's talk about
dementia*



While we do everything that we can to raise awareness of dementia all year round, Dementia Awareness Week is our annual opportunity to share a more focused overview of our work and encourage people to support us so that we can continue to make sure nobody faces dementia alone.

Reflecting on the devastating impact, and the lived experience of coronavirus on the dementia community, this year's Dementia Awareness Week explored 'hidden voices, hidden impact, hidden cost'. We updated and republished our 'COVID-19: the hidden impact' report. This sets out the evidence gathered from people with dementia and their carers we have supported throughout this crisis, about the impact of the pandemic, and the unintended harms to their health and wellbeing caused by the measures intended to keep them safe. This report is available to read on our website.

We launched a forget-me-not pledge campaign where we asked people to download a flower graphic, write their pledge on it, then tweet their picture holding the image. We were delighted to see all the pictures on social media, from schoolchildren to NHS staff, proudly holding up their pledges.

We asked people to 'make a difference in a matter of minutes' by downloading our Purple Alert app, signing up to Join Dementia Research, signing up to Join Dementia Research, completing Brain Health Scotland's online course, subscribing to our enews, sharing their stories with us, following us on social media, becoming a Dementia Friend, or by making a donation.

Each day of the week had a different theme and we covered topics such as research and prevention, innovation,

campaigning for change and keeping connected. We shared stories and blogs from some of the amazing people that we support, as well as from Alzheimer Scotland frontline staff. We heard about the impact that post diagnostic support can make, the difference that our Helpline staff and volunteers can make to the lives of callers, and the importance of digital connection throughout the pandemic.

We were overwhelmed by the support that we received this year, from people holding their own fundraising events to buildings being lit up purple for the week, llamas sporting our tartan scarves and even a live streaming of the 'Night Fever' exhibition from the V&A in Dundee. Thank you to everyone who got involved in raising awareness of dementia and supporting our work.



Alzheimer Scotland Annual Conference 2021

Moving forward together – what matters to people with dementia, families, carers & practitioners, now and in the future

Our Annual Conference took place on Tuesday 21 September which was also World Alzheimer's Day. The event was held digitally and was streamed via the Edinburgh International Conference Centre (EICC).

Our Chief Executive, Henry Simmons, opened the event with his keynote speech where he spoke about Alzheimer Scotland's strategic direction and vision for transformation.

This was followed by Scotland's Dementia Awards and the Lifetime Achievement Award for Archie Noone – you can read our tribute to Archie on page 7.

A 'What Matters to You?' panel discussion with the Minister for Mental Wellbeing and Social Care, Kevin Stewart MSP and Scotland's National Clinical Director, Professor Jason Leitch, was held, where they answered questions that had been asked by people living with dementia, their carers and families on the issues that mattered to them. The session was hosted by Alzheimer Scotland Ambassador, former STV journalist, Mike Edwards.

The afternoon session saw presentations on drug discovery and research, brain health and prevention, as well as the formal launch of the UK's first Virtual Resource Centre and a very popular Doggy Bingo session.

On the days following the conference, we held 'follow on sessions', a series of workshops, webinars and drop-in sessions on a range of subjects including brain health, the Dementia Champions programme, post diagnostic support and Dementia Friends.

The feedback from both the conference and the follow-on sessions was very positive, with many people saying how much they appreciated being able to attend an event without the difficulties of having to travel.

Thanks to all who presented and attended.

"Good to hear the positive and consistent commitments and the vision for the future. Minister questioning was chaired very well by Mike Edwards, and I felt that Kevin Stewart MSP really did listen and take on board concerns raised."

"A very appropriate and relevant speech, both heartfelt and meaningful."

"Excellent overview of the way forward."

"Living outside the UK I was delighted to have the opportunity to attend virtually, the whole day was run very efficiently and very enjoyable. I liked the fact I could leave at certain points for essential reasons but easily rejoin when I was able. Well done to everyone on a very successful first virtual conference."

Our conference sessions are still available to view on our website here

www.alzscot.org/alzheimer-scotland-annual-conference-2021

Introducing our Action on Rights team

By Lorna Hart-Thomson, Action on Rights Team Leader, Alzheimer Scotland

Alzheimer Scotland's Action on Rights team, funded by the Scottish Government, was set up in March 2021 to help carers, families, and friends of anyone living in Scotland's care homes. The team aims to support meaningful contact between those living in care homes and their families and friends. Where necessary and appropriate, our Action on Rights team can also liaise directly with care home staff responsible for visiting arrangements to help facilitate visits (when permitted and within any relevant restrictions). They also help people to be better informed about care home visiting guidance, local public health restrictions and support available, and can support people to make more informed decisions and have better conversations with care homes around visiting.

To date, we have had over 240 referrals, and during the last 9 months, the team has been dealing with complex and understandably highly emotional cases. Many callers have been experiencing emotional distress from a lack of meaningful contact with family members or friends living in a care home.

People have found variations with the interpretation and implementation of the Open with Care guidance for example, care homes creating their own guidance which departs from the national guidance, additional restrictions on visits such as strict time limits of 30 minutes, and some care homes not allowing visits at all.

Despite the negative experiences that many people have shared, the team want to let anyone who has a loved one in a Scottish care home know that visiting is much more flexible than before. People can now have regular visits, have indoor visits with loved ones, have families and friends visiting within their own bedroom, and go out for a day trip or overnight to see family and friends.

Family members and friends planning a visit can now take a lateral flow test at home and provide evidence of a negative status at the care home. They can also ask for 'Essential Visit Status' if there are signs of distress (for the resident or relative), deterioration or end of life.

'Named Visitor Status' can also be requested if there is a managed outbreak – this allows one member of the family to visit. It is worth noting that if infection rates are high in some areas, the care home may not permit any visits.

For anyone having issues with visits, we strongly advise having a conversation with the care home in the first instance. If you are still having difficulties seeing your loved ones, please contact the Action on Rights team and we can liaise with the care home on your behalf if required.

You can reach the Action on Rights team via our 24 hour freephone Dementia Helpline on **0808 808 3000** or email actiononrights@alzscot.org

From a family member
'I didn't want to contact Action on Rights because I didn't want to make a fuss, however, I am so glad I did as now I am getting Essential Visit Status.'

From a family member
'Just speaking to Action on Rights gave me the confidence to have the conversation with the Care Home Manager, that little bit of reassurance meant I get to see dad more often.'

240

Referrals to date



Over

2,500

interactions with families



14

Engagement groups



Keeping connected – our 24 hour Dementia Helpline

By Jennifer Hall, Head of National Support Services, Alzheimer Scotland

Alzheimer Scotland's Freephone Dementia Helpline has continued to operate 24-7 throughout the pandemic. Since the first lockdown on the 23 March 2020, our highly skilled Helpline staff and volunteers have taken over 15,000 calls and provided over 1,964 hours of support. That is the equivalent of 82 consecutive days of them providing a listening ear, emotional support, information and signposting to other resources.

Our Helpline is often the first point of contact for people living with dementia, carers, concerned family members or friends, as well as people who are worried about dementia and not sure what to do next. Over the course of the pandemic our Helpline team have listened carefully to the lived experiences of our callers, and we have responded as best we can by ensuring that we have a range of services and support that can meet their needs.

As a result of this, we now have our Action on Rights

team, funded by the Scottish Government and dedicated to supporting the implementation of their 'Open with Care' guidance. This team are working to ensure that families have meaningful contact with their loved ones living in care homes.

The second new development is the creation of our National Counselling Service, also funded by the Scottish Government. This service has two dedicated Counsellors supporting people across Scotland who are either living with or caring for someone with dementia. If you would like to know more about this service and how to access it, please contact your local Dementia Advisor or call our Dementia Helpline on 0808 808 3000.

Our Helpline would simply not exist if it wasn't for the dedication and time given to us by our volunteers. For information on how to become a Helpline volunteer please visit our website.

www.alzscot.org/volunteer-with-us



Since March 2020 our Helpline has taken over

15,000 calls

Provided over

1,964

hours of support



24 HOUR

 **Alzheimer Scotland**
Action on Dementia

Dementia Helpline

Freephone 0808 808 3000
Email helpline@alzscot.org



We believe a little bit of magic goes a long way

Our 2021 Winter Fundraising Appeal

By Jessica Bruce – Communications & Campaigns Officer, Alzheimer Scotland



We launched our Winter fundraising appeal in late November. You can find one of our 'stars', Iain Fraser, gracing the cover of this magazine. Rather than simply showcase our services, we wanted to convey the essence of our support – less of the 'what we do' and more of the 'why we do it'.

No one knows more about the 'why we do it' than our fantastic frontline colleagues. After some informal chats, we were able to identify some wonderful people with lived experience who were keen to support the campaign.

Enter Iain and Danny, and Danny's wife Catherine.

I had the privilege of chatting to them all as part of our campaign planning. There was something special in their anecdotes, and in the small details that could be easily overlooked – tiny moments of magic. It was from these chats that our campaign strapline was born...

'The little moments of magic make such a difference.'

Our colleague, Dementia Advisor Karen Black, supports Iain and features in the campaign. Karen sums it up perfectly when she says "It's when someone feels so comfortable in our Dementia Resource Centre that they take off their shoes and make themselves at home. The spontaneous dancing. The laughs and the giggles."

We kept the filming very simple and purely focused on the experiences of our 'stars'. As well as producing very short video films to show on our social media channels, we sent a letter from Iain and Karen to the people on our database. A second letter from Danny will feature on our website. Working with them all on these letters was such an inspiring process.

We went through those letters line by line – Iain's final edit was asking us to add in the line "thank you for taking the time to read my letter." It was amazing to see how determined he was to get his letter word perfect.

On his experience in taking part in the campaign, Iain said:

"I have thoroughly enjoyed every single minute of doing this. I didn't know I had it in me! You have no idea what this has done for me."

Danny also enjoyed the whole process, saying:

"I found the experience educational and inspirational."

"As a member of our Communications and Campaigns team, the magic for me was the opportunity to work with and co-produce all the elements of the Winter fundraising appeal with these amazing people and having the opportunity to help them tell their story." Jessica Bruce

Since March 2020...



15,000

calls taken by our
24h Freephone
Dementia Helpline



20,000

support interventions
provided by our
Dementia Advisors



250

active community
groups attended by
over 2,000 people



22

Dementia Resource
Centres across
Scotland

“Danny’s still Danny. He’s still got a wicked sense of humour. He’s still very tactile. He’s still very loving. He’s still my husband”
Catherine MacDonald



To view both Danny’s and Iain’s stories, and find ways in which to support our fundraising appeal, visit magic.alzscot.org or scan the QR code.

Chris Laidlaw's 12in12 challenge

By Sarah Cheung, Stakeholder Engagement Leader, Alzheimer Scotland

Chris Laidlaw, 30, has been running 12 marathons throughout 2021 to raise funds for Alzheimer Scotland. Chris, a Scotland Club XV International and academy coach is also the youngest son of one of Scottish Rugby's all-time greats, former Scotland and British and Irish Lions scrum-half Roy Laidlaw. Sadly, Chris lost his mum Joy to cancer in 2020, the same year that his father Roy made his diagnosis of Alzheimer's disease public. In memory of his mum and to honour his father, Chris chose three charities to support: Marie Curie, Murrayfield Injured Players' Foundation and Alzheimer Scotland.

The '12in12' challenge began on New Year's Day 2021 and has continued each month with his final marathon scheduled for New Year's Eve.

You can support Chris with his 12in12 challenge by donating to his Crowdfunding page: justgiving.com/crowdfunding/12in12in21 and follow his journey at twitter.com/laidlaw9



Chris said:

"It's by far one of the best things I have decided to do in my life so far. It's given me a strong purpose and drive to take on my challenge and raise awareness and funds for Alzheimer Scotland. The sense of doing something for others really motivates me. The support you get from friends, family and the wider public is fantastic and the team at Alzheimer Scotland are brilliant in supporting and communicating to make it as easy as possible to fundraise for them."



Chris now has 11 marathons under his belt, and he shared with us:

"The highlight so far must be getting across the finish line and seeing my wife and kids. The emotions have been strong when crossing the line for several reasons but to know they are waiting for me at the end really spurs me on to get there."

Sarah Cheung, Stakeholder Engagement Leader said:

"We are so honoured that Chris has chosen to support Alzheimer Scotland for his inspirational 12in12 challenge, and we commend both Roy and Chris for speaking out to raise awareness."



Braehead becomes Scotland's first dementia friendly shopping centre

By Aileen Turnbull, Stakeholder Engagement Leader, Alzheimer Scotland



Alzheimer Scotland has partnered with Glasgow's Braehead Shopping Centre, which we celebrated with a week of activities in early October. This included members of the public having the chance to speak to Alzheimer Scotland Dementia Advisors and take part in daily Dementia Friends sessions. It was a great opportunity for us to highlight the services we provide and show how we help support people living with dementia, their carers and families.

We were overwhelmed by the support shown not only by the retailers, but also the public with their generous donations in our bucket collection. The Alzheimer Scotland pop-up

shop, which featured our new line of merchandise, also proved popular with Braehead shoppers. Alzheimer Scotland will continue working with retailers in Braehead, encouraging their staff to take part in our Dementia Friends sessions. This will make the overall Braehead experience easier and more enjoyable for people living with dementia, their carers, families and friends.

This is an exciting partnership for Alzheimer Scotland, which will see Braehead as Scotland's first Dementia Friendly Shopping Centre. We look forward to developing more partnerships like this in the future.

Braehead has also downloaded Alzheimer Scotland's Purple Alert app onto staff phones and linked this into their Centre's control room to help find someone with dementia if they are lost. For more information on Purple Alert see page 22.



Memory Walk 2021

– an incredible £112,000 raised

By Sarah Cheung, Stakeholder Engagement Leader, Alzheimer Scotland



This year, Scotland's Memory Walk welcomed hundreds of participants taking part in our annual September event in honour and in memory of loved ones, and to fundraise for Alzheimer Scotland.

Participants were encouraged to choose their own route, many of which held a significant meaning or memory. People took part from all over Scotland, as well as internationally, including walkers from Hong Kong, New Zealand and Canada.

Our ambitious fundraising target of £90,000 was surpassed by a remarkable 24% with our team of dedicated walkers raising over £112,000 for Alzheimer Scotland.

Thanks to this fundraised income, we can continue to be there for people from before diagnosis through to end of life care. Income from Scotland's Memory Walk will enable us to support people like Margaret through our Dementia Resource Centres and other services. Margaret explains:

"When the diagnosis hit, I was actually lost, and it was a very sad time for me. Being able to hook into the Dementia Resource Centres and other people was essentially a lifeline. I didn't want to get involved with groups at the start of it but once I was in there it was a warm and very comfortable group that I was with. They made me so welcome that I looked forward to going again the next week. I've actually found friends through this as well."

With the introduction of a new fundraising platform, participants were able to sign up for free.

gain access to resources and fundraise in one place to make the experience easier and more enjoyable. People were invited to connect with the charity and fellow supporters via a dedicated Facebook group.

With two successful events now in the new virtual format, participant feedback shows that despite walking their own route, people actually feel more connected than ever to our charity aims, and we are excited to announce that next year's walk will continue to use the virtual format.

One participant shared:

"This year was particularly poignant as it was around my mum's home area- I felt this was much more of a 'memory' walk than an organised event."

Alzheimer Scotland would like to extend a heartfelt thank you to everyone who supported Scotland's Memory Walk and we hope to welcome you back in 2022.



You can register your interest to take part in Scotland's Memory Walk 2022 by visiting our website: memorywalk.alzscot.org

Our corporate partnerships – an update

By Caroline Miller, Lead for Stakeholder Engagement, Alzheimer Scotland

With restrictions easing, our corporate partners have been eager to get back out there and support Alzheimer Scotland. They really have gone the extra mile – here is a snapshot of what has been happening and just some of our exciting plans for the future.

ARRAN Sense of Scotland

We were delighted to launch a new partnership with ARRAN Sense of Scotland who produce home, bath and body products, all manufactured on the Isle of Arran. They are keen to support our outdoor therapeutic work as their mission is to help people create meaningful connections with nature. They generously supported us by sponsoring t-shirts for our Memory Walk, and then went on to raise over £15,000 by completing their own walk over on the Isle of Arran. In addition to this, they are providing us with products to sell in our new shop and their staff recently became Dementia Friends. We are also working with them to make their business more accessible to people living with dementia.

Fosters Funeral Directors

Colleagues from Fosters Funeral Directors also took part in our Memory Walk and raised over £2,500. We are also extremely thankful to them for promoting Alzheimer Scotland as part of their current advertising campaign – helping us to reach more people who may need our support.



ARRAN Sense of Scotland colleagues still smiling after their rainy walk

Brodies and Gillespie Macandrew

Our corporate partners in the legal field have been supporting us by offering some ad-hoc advice. Legal firms Brodies and Gillespie Macandrew have written blogs and delivered webinars to our Helpline and Action on Rights staff and volunteer teams on topics such as Guardianship and Power of Attorney. This advice has been invaluable as our teams have been dealing with increasingly complex situations highlighted by the pandemic.

Scottish Chamber Orchestra

During lockdown we were fortunate to work with the Scottish Chamber Orchestra. They supported people living with dementia in the Fife area by running their 'Reconnect' programme of online music sessions, bringing music into people's homes. We are now delighted to announce that we will be the charity partner of the Scottish Chamber Orchestra for the next three years and will be the beneficiary at their annual gala concerts.

We are so grateful for the support of our corporate partners who have continued to give their time and fundraise for Alzheimer Scotland throughout this challenging period.

If you'd like to talk to us about how your company can help us support people living with dementia please contact cmiller@alzscot.org

Nick surpasses the halfway point of inspiring 282 Munro challenge

By Isabel Quinn, Stakeholder Engagement Coordinator, Alzheimer Scotland

Nick Gardner from Wester Ross set himself a demanding and exhilarating challenge to climb all of Scotland's 282 Munros over 1,200 days.

Nick was motivated to take on this huge challenge for his wife Janet, who has vascular dementia and now lives in a care home. He has been a keen walker and hill climber all his life and is always happy when he is in the hills.



Nick explained:

"I wanted to do something to benefit people with Alzheimer's disease and carers everywhere. I was approaching my 80th birthday and thought that climbing all the Munros in my eighties would be a good challenge! My challenge is to raise £10,000 for Alzheimer Scotland and I'm sure my 80-year-old legs are up to the feat, but only time will tell!"

To date, Nick has completed his 185th Munro and raised over £35,000 for Alzheimer Scotland and the Royal Osteoporosis Society. Nick has also raised awareness of both charities as he welcomes friends, family and members of the public to join him during his climbs.

Nick shared his advice for anyone thinking of fundraising for Alzheimer Scotland,

"Sadly, this is an illness on the increase and Alzheimer Scotland relies on charity in order to provide vital care, support and research. I know first-hand how traumatic it is to care for a loved one, and the more money that goes to this cause, the sooner a cure can be found. Therefore, if you're thinking about fundraising, please 'Go for it!'"

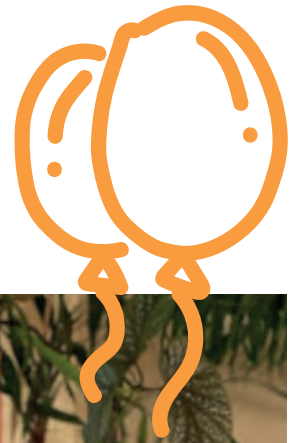
You can follow Nick's challenge and show your support via facebook.com/nick.gardner.nmc1200

Feeling inspired?

Take on a challenge of your own and join our Do it for Dementia campaign alzscot.org/do-it-for-dementia

 Do it for
dementia

Happy 90th birthday Teresa



By Jonathan Mitchell, Lead for Stakeholder Engagement, Alzheimer Scotland

A huge thank you to Teresa Crawley who celebrated her 90th birthday by donating a fantastic £1,000 to Alzheimer Scotland. Instead of gifts, Teresa asked for donations to Alzheimer Scotland from all her family and friends to celebrate this special occasion. This generosity comes ten years after Teresa celebrated her 80th birthday and again raised money for Alzheimer Scotland and three other charities close to Teresa's heart. Friends and family came from far and wide to celebrate with Teresa who said, "It was a great day and I want to say thank you to all my friends, relations and neighbours who donated." Here at Alzheimer Scotland, we are amazed by the kindness of not only Teresa, but also her family and friends and we want to thank them all for their support.



**As a new year approaches,
so does a new challenge!**

This January we invite you to join our new fundraising challenge to complete 90,000 steps. This is a feel good challenge and you get to set the pace.

Around 90,000 people are living with dementia in Scotland right now and thanks to amazing fundraisers like you, we can continue to support them.

It's so easy to get involved.

Sign up now for early access to our Facebook group to meet our other participants and gain access to your fundraising tools.

www.facebook.com/groups/90kstepschallenge

**90K
STEPS
CHALLENGE**

Purple Alert news and the Herbert Protocol launch

By Tommy Petillo, Purple Alert Coordinator, Alzheimer Scotland

Staying active and maintaining social connections are good for all of us and should be part of a healthy routine, however getting out and about safely on your own can become more challenging when living with dementia. There are many ways you can make sure you or your loved ones are safe when out and about, from carrying a mobile phone, to using technology such as GPS devices. Purple Alert is a free app designed by Alzheimer Scotland to help find people with dementia if they are missing. The app allows users to create a profile of the person living with dementia and share it with the local community. Everyone in the area who has the app on their phone will get notified and can actively help with the search. If a member of the public finds the person, they can then use the app to get in touch with the carer or family member. Alzheimer Scotland developed Purple Alert very closely with Police Scotland.



Caring for someone with dementia?
Worried that they may go missing?

The Herbert Protocol is similar to Purple Alert, but is a paper form in which all the vital information about someone with dementia is recorded. The document is kept safe by the person's carer or family member and shared with Police Scotland if the person is missing. Since 2017, the Herbert Protocol has been used many times to help police and other agencies quickly and safely locate missing people who have dementia. The initiative was rolled out nationwide from 21 September 2021.

Morag Francis is a carer for her mum, who has a diagnosis of dementia, and her family has already downloaded Purple Alert and completed a Herbert Protocol form.

Morag said:

"We did it as a little project with mum because it was about her life, so it turned into a bit of a reminiscence session, so we could pinpoint areas that were still important to her. We could guess most of them because she did talk a lot about the past, but we wanted to make sure we'd thought of all the areas she might turn up at because that's where she remembered."

To me it's my insurance document, because I appreciate if we couldn't find her the levels of stress would be incredible and we wouldn't really be able to think straight."

Purple Alert
Looking out for you

Have you downloaded Purple Alert?

www.alzscot.org/PurpleAlert

THE
**HERBERT
PROTOCOL**
Safe & Found



**POLICE
SCOTLAND**
Keeping people safe
POILEAS ALBA

Download the form and find out more at:

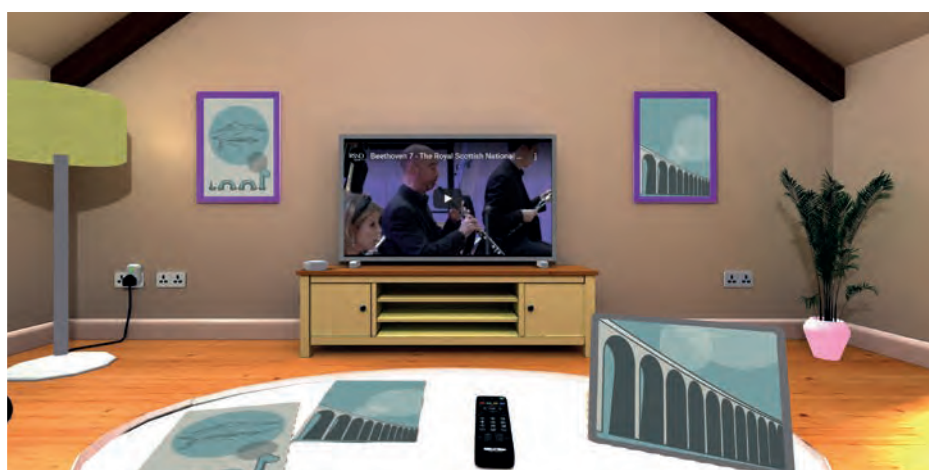
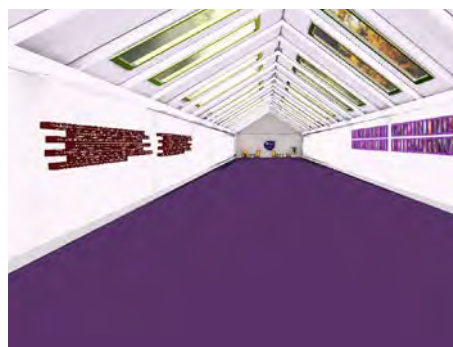
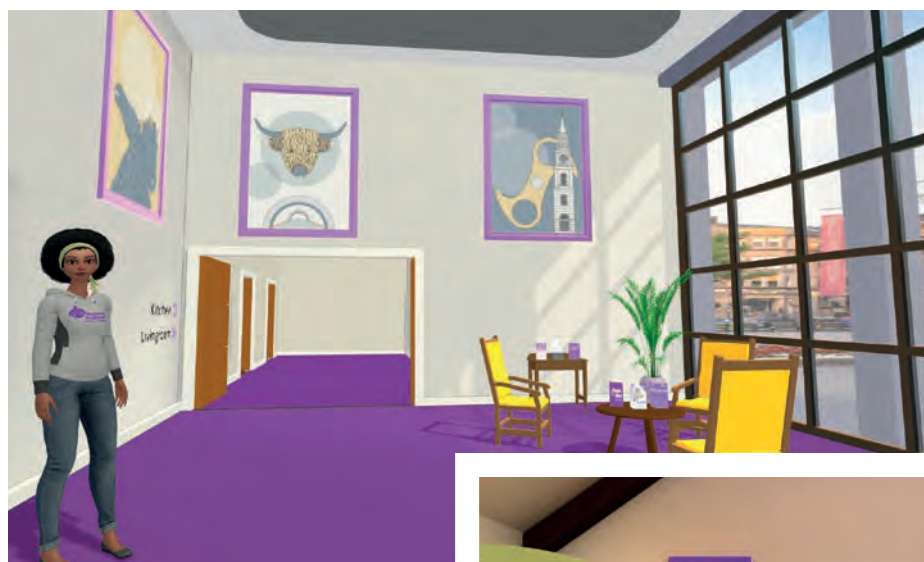
www.scotland.police.uk/herbertprotocol

or scan the QR code:



The UK's first Virtual Resource Centre opens its digital doors

By Kevin Jamieson, Virtual Resource Centre Coordinator, Alzheimer Scotland



Alzheimer Scotland launched the UK's first Virtual Dementia Resource Centre on Tuesday 21 September – World Alzheimer's Day 2021. The Virtual Resource Centre will offer people with dementia and their families and carers, online access to many of the resources of a traditional Dementia Resource Centre, without the constraints of distance, travel and opening times.

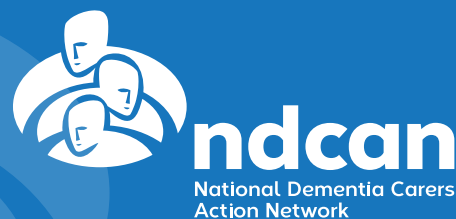
Thank you to everyone who donated to our Virtual Brick appeal to allow us to get to where we are. We are extremely grateful for this support.

Our team behind the scenes are working hard on the development of the Centre. This includes video conferencing which will allow our visitors to book and join one-to-one video calls with Dementia Advisors and Allied Health Professionals. Video conferencing will also give visitors the chance to connect with Alzheimer Scotland community groups and activities remotely, which is so important for people living with dementia who may not be able to get to a physical Dementia Resource Centre.

Our aim is to ensure that the Centre is thoroughly developed and tested by people with dementia and their carers. If you are interested in testing some of the features of the Virtual Resource Centre, such as the navigation, general design, accessibility and content, please contact Kevin Jamieson, our Virtual Resource Centre Coordinator at kjamieson@alzscot.org

Meantime, you can visit and explore the current resources on offer at www.alzscot.org/virtual-resource-centre

A decade of campaigning for carers



By Caroline Russell, Communications & Campaigns Officer, Alzheimer Scotland

The National Dementia Carers Action Network (NDCAN) is a national campaigning and awareness raising group for carers and former carers of people with dementia living in Scotland. For a long time, carers and families had been telling Alzheimer Scotland that the system was not meeting their needs and failed to recognise the unique nature of caring for someone with dementia and the particular challenges it could present – and as a result the group was formed in 2011.

Around this time, Tommy Whitelaw, a carer for his mum, had started a blog talking about his experiences and asking other carers of people with dementia to send him their life story letters. Tommy spent a week walking around Scotland collecting these letters and the 'Tommy on Tour' campaign began.

An event was held at the Scottish Parliament for Tommy to deliver his letters. At this event, Alzheimer Scotland's Chief Executive, Henry Simmons, spoke about the need to establish a platform for carers to have a voice and committed to developing a group to do this. Carers attending the parliamentary event were invited to join this new network which became NDCAN.

The very first NDCAN meeting was held in late November 2011. Former MSP and current Director of Strategy and Engagement at The Alliance, Irene Oldfather was later elected as Chair, and successfully led NDCAN in this role until 2015.



Since the beginning, NDCAN members have worked tirelessly to make the voices of carers heard and to raise awareness of the issues that impact on their day to day lives. There have been some amazing achievements over the last ten years.

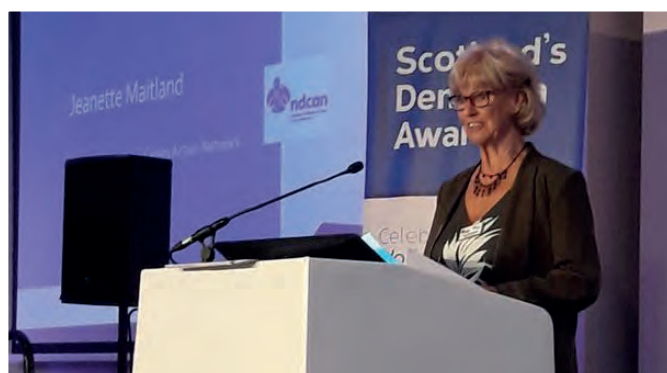
NDCAN members have met regularly with Ministers and fed into government consultations, as well as sitting on the national boards for both the National Dementia Strategy and the Carers Act to ensure carers' voices were heard and listened to. NDCAN has helped to improve the quality of care for people with dementia, working with Focus on Dementia to improve the quality of post diagnostic support, providing representation on groups looking at the transformation of specialist dementia units and delivering hospital care. Members have shared their own lived experiences with health and social care professionals, so they are aware of what support carers need.

Each year, NDCAN members have been involved in the Dementia Champions Programme, an initiative that aims to improve the experience of a person with dementia whilst in a hospital setting, again providing their own thoughts and personal stories to healthcare professionals.

Members have attended and presented at conferences in Scotland, the UK and abroad to raise awareness at a local, national and international level, travelling to Vienna, Slovenia, Copenhagen, Berlin and even Puerto Rico.

In 2016, members of NDCAN developed a series of eight resilience booklets 'For Carers, By Carers'. In these, carers shared what has helped them get through the day and cope with difficult times. They have also contributed to the development of resources for carers on a range of subjects, including younger onset dementia, continence and speech therapy.

on this special anniversary, Alzheimer Scotland would like to congratulate the NDCAN Committee and network members and thank them for all their hard work over the last 10 years.



'NDCAN has given me the opportunity to make a positive difference to the lives of people with dementia and those who care for them.' – Maureen Huggins

NDCAN also supported Alzheimer Scotland's Fair Dementia Care campaign, calling for an end to the inequities that people living with advanced dementia face, in terms of accessing healthcare.

Over the years, members have gained so much from working with each other, and some strong friendships have evolved from the network. Knowing that they are making things better for the current and next generation of carers is so important to them.

NDCAN Members, Jeanette Maitland and Lorna Walker, who have been part of NDCAN since the beginning, have offered their reflections on what NDCAN has meant to them:

'As we celebrate today, it allows us 'this time' to stop, even for a minute- to recall, reflect and embrace, some of our achievements and losses over this past decade.' – Lorna Walker

'Being a member of NDCAN helped shape our way of thinking and we have learned so much over the past 10 years. Not least, all of us becoming empowered, making our voices heard and sharing our stories.' – Jeanette Maitland



NDCAN is currently looking for new members

Are you passionate about improving the rights of carers and having their voices heard?

The group is open to anyone living in Scotland who has experience (current or former) of caring for a person with dementia. By joining NDCAN, you will be part of influencing the future of dementia policy and strategy in Scotland, helping to make things better for the next generation of carers. If you are interested in joining, or would like to know more, please email: NDCAN@alzscot.org

Understanding Brain Health

By Neil Fullerton, Project and Communications Lead, Brain Health Scotland

The mission of Brain Health Scotland is to inspire and empower everyone to protect the health of their brain and reduce their risks of diseases that can lead to dementia.

Here, we catch up with the progress on three of our initiatives which, through education, a roadmap forward, and providing a practical toolkit, all help build towards this mission.



An Understanding

Understanding Brain Health: Preventing Dementia is a free, open online course, developed by Brain Health Scotland in partnership with the University of Edinburgh. The course runs across four weeks and features an engaging mix of video clips, articles to read and short interactive quizzes to check understanding.

The course is hosted on the FutureLearn platform, and can be completed on a computer, tablet or mobile. Each topic on the course is split up into small individual steps, allowing learners to go at their own pace and fit learning flexibly around their life.

Since launching in March this year, more than 2,500 people from across 100 countries have signed up for the course and you can join them.

To find out more and to sign up for the course, visit:

www.brainhealth.scot/resources



"We hope through engaging with this course learners will understand more about brain health and the factors that can put it at risk. We will explore the diseases that lead to dementia and how researchers, clinicians and the public can work together to unlock the benefits of taking positive, lifelong brain health action."

Anna Borthwick,
Executive Lead of Brain Health Scotland



THE UNIVERSITY
of EDINBURGH

A Route

The online course features lots of information on brain health and dementia research, past, present and future.

The direction of travel for this research in Scotland has recently been set out in the first Scottish Brain Health & Dementia Research Strategy. The strategy was developed in partnership between the Scottish Dementia Research Consortium, Alzheimer Scotland and Brain Health Scotland and has been widely endorsed by many leading national organisations. It makes several key recommendations for creating more effective and more impactful research outputs across Scotland, with the ultimate aim of laying the groundwork to create a long term, sustainable environment in which brain health and dementia research can flourish. Find out more about the future of brain health and dementia research in Scotland at:

www.brainhealth.scot/post/researchstrategy

We are all researchers

Scottish Brain Health
& Dementia Research Strategy

A Plan

A core theme running throughout the research strategy is that 'we are all researchers'. This means that everyone should be empowered and enabled to make a meaningful contribution.

This is a view shared by Brain Health Scotland and central to our belief that everyone should have access to the necessary tools to understand and take ownership of their own brain health.

To help guide making positive changes that can benefit brain health, and importantly to help with sticking to these changes, Brain Health Scotland has launched 'My Brain Health Plan'.

Focusing on six key areas for action (right), My Brain Health Plan encourages everyone to make personal pledges which can help address areas of daily life important for maintaining brain health.

My Brain Health Plan helps give ownership of brain health to the individual and also features an online community to get inspiration from others and to facilitate sharing of pledges and progress virtually.

Exercise

Getting active and reducing the amount of time we spend sat still



Socialising & learning

Keeping socially active with friends & family and continuing to learn new skills throughout life



Rest

Getting a regular 7–9 hours good quality sleep every night and managing stress in our daily lives



Food

Eating a good balance of foods, particularly following a more Mediterranean-style diet



Harms

Avoiding smoking and limiting the amount of alcohol we drink



Medical fitness

Following advice from healthcare providers closely and keeping on top of existing medical conditions



Brain Health Scotland is working with policy makers, healthcare providers, businesses, and education initiatives to build environments across Scotland which make it easier to lead brain-healthy lives. Join the brain health community, visit www.brainhealth.scot/brainhealthplan and start your brain health plan.





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