

Dementia in Scotland

Autumn 2020 – Issue 101



40 years
of innovation,
compassion &
community



Worried about dementia?

24 HOUR
Dementia
Helpline

Alzheimer Scotland
Action on Dementia

Freephone 0808 808 3000
Email helpline@alzscot.org



Making sure nobody faces dementia alone.



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Welcome

It's my pleasure to welcome you to this edition of Dementia in Scotland. The world that we live in is remarkably different to the last time you read this magazine, with the impact of the coronavirus pandemic. This was felt especially in our dementia community with many of the people we support either in the shielding or high-risk category. You will read in the magazine how Alzheimer Scotland altered our support during lockdown and I would like to say a sincere thank you to our colleagues, volunteers and especially people with dementia, carers and families for adapting to the changes we simply had to make. I must also pay tribute to the frontline staff, including many Alzheimer Scotland workers, who demonstrated incredible dedication and commitment in the toughest of times.

The last magazine, published in November 2019, celebrated 100 editions and we now have an even bigger occasion to mark with our 40th anniversary. It's remarkable to think of the progress that has been made in those years. We now live in a world where the person is at the heart of everything we do; our rights-based approach has significantly helped to reduce the stigma and discrimination that was faced by people with dementia previously. Whilst we have some way to go to ensure our vision for transformation is implemented consistently throughout Scotland, I am really proud of the work that has been carried out in the last 40 years. On p20-21 you can see how Alzheimer Scotland has grown over the decades, the partnership working that has been undertaken and some of our biggest achievements.

A world where some types of dementia are preventable has always been a goal for Alzheimer Scotland. It gives me great pleasure to introduce

Brain Health Scotland, which will be led by Professor Craig Ritchie in collaboration with many other stakeholders. Brain Health Scotland will look at creating Scotland's first Brain Health Strategy and Alzheimer Scotland will play a crucial role, hosting and supporting its development and implementation. You can read more about this pioneering work on p24-27.

Alzheimer Scotland pride ourselves on being an innovative charity; always forward-thinking and focusing on creative ways to support people with dementia. This is especially relevant to our digital and technological solutions and on p28-31 you can get an update on just some of the new digital products and services we have been working on. This includes a Virtual Dementia Resource Centre which feels more pertinent than ever given the circumstances. By the time you read this, we will have launched a public campaign for the Virtual Centre and we hope that, as a result of this, no matter where you are in the world, you will be able to access our support. It really is an exciting development.

The virtual theme continues and I must say a big well done to everyone who completed a challenge as part of our 'Do it for Dementia' virtual event series. This was launched during lockdown and an incredible amount of money has been raised so far. This level of support is vital at a time where most challenges and fundraising events were cancelled - thank you ever so much.

Stay safe and well.



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, Dawn Ferguson, by email: dferguson@alzscot.org or by phone: 0141 410 0108.

Alzheimer Scotland is a proud signatory of the Digital Participation Charter.

This means that we are committed to ensuring that people living with dementia and their families have access to digital support and expertise across Scotland.



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News from Alzheimer Scotland

The coronavirus pandemic significantly impacted much of the work that we, and our partner organisations, were planning in 2020. However, as always, we do have some news updates for you. Here is a snapshot of just some of Alzheimer Scotland's news since we last updated you in November 2019.



At the beginning of the year we launched our report, **'Connecting People, Connecting Support in Action: An impact report on transforming the Allied Health Professionals' (AHPs) contribution to supporting people living with dementia in Scotland'** in partnership with the Scottish Government, at a celebratory launch event at the University of the West of Scotland. The report charts the vision, principles, ambitions and actions of the Connecting People, Connecting Support national framework over the first 24 months since launch and the progress that has been made by the AHPs.



On 27 February NHS Education for Scotland (NES) launched its report, **'Driving Improvements in Specialist Dementia Care'**. The report highlights the achievements of 121 participants from three cohorts of the NES Dementia Specialist Improvement Lead programme between 2014 and 2020. Through case studies and personal reflections, participants demonstrated how the programme has equipped them to drive and effect changes and improvements that support the transformation of specialist dementia care in Scotland.



April saw the Stirling and Clackmannanshire Branch of Alzheimer Scotland meet and exceed their £100,000 target to help fund a new Dementia Resource Centre. The full community got behind the mammoth year-long fundraising campaign, which included afternoon teas, ceilidhs and a St. Patrick's Night. The renovation work for the new Centre, which will be based in Mill Street, Alloa, started in August and we look forward to sharing its opening date soon.



On 24 February, Join Dementia Research celebrated its fifth birthday which has seen over 45,000 people across the UK register with the service. As of February 2020, dementia studies have filled over 25,000 study places using the register - 27,807 in total. You can find out more about Join Dementia Research by visiting: <https://www.joindementiaresearch.nihr.ac.uk/>.



In March, another 98 Dementia Champions and 45 Dementia Specialist Improvement Leads (DSIL) graduated from specialist dementia training programmes aimed at improving the care and support for people living with dementia in Scottish hospitals, care homes and community settings.



The Scottish Dementia Research Consortium (SDRC) launched their 2019/20 annual report at the end of April. The report outlines what's new in dementia and brain health research in Scotland in the past 12 months. It also demonstrates the amazing quantity, quality and diversity of research happening throughout the country in addition to our international collaborations.

If you'd like to find out more about any of these news stories, please visit www.alzscot.org/news

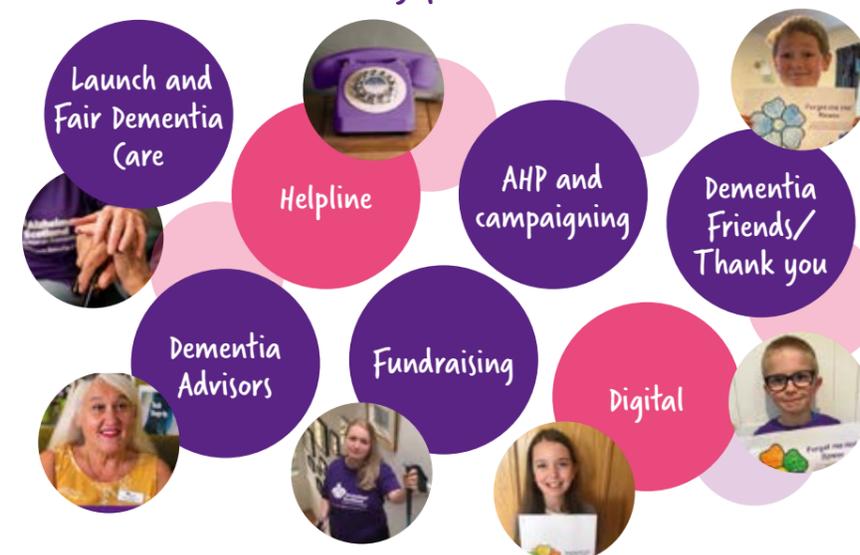
Dementia Awareness Week during a pandemic

By Dawn Ferguson, Content Manager, Alzheimer Scotland

Dementia Awareness Week is normally the highlight of Alzheimer Scotland's calendar. It is the one focused week of the year where the full dementia community comes together; from people with dementia and carers to staff, volunteers and supporters. The week is our chance to shine a spotlight on dementia and ensure that as many people as possible know about the disease. We also showcase what Alzheimer Scotland are doing to make sure nobody faces dementia alone and show our support for people living with dementia and their families. Up until the beginning of March we were full steam ahead in planning the biggest and best Dementia Awareness Week yet, which would have launched with our Annual Conference and included lots of locality and supporter led events, collaborative working and the opportunity to raise funds and awareness.

The coronavirus pandemic meant all plans we had were understandably cancelled. We knew that we couldn't let the week pass by without marking it in some way and so we moved to a predominantly online focus. We used Dementia Awareness Week as an opportunity to talk about some of Alzheimer Scotland's key work streams and really encouraged conversation amongst our community. We also worked closely with some of our colleagues, including our Allied Health Professionals and Dementia Nurse Consultants to provide an array of high-quality information.

"We're still here, still care, and still doing all we can to make sure nobody faces dementia alone."



As well as showcasing some of our work, we also asked our supporters to decorate and display a forget-me-not flower in windows across Scotland. We were overwhelmed with the response; photos of thousands of brightly coloured flowers were sent in to us from children, adults, hospital staff and care homes, to name a few. This small act of kindness really demonstrated the support for those living with dementia and their families, as well as generating awareness of the disease and of our charity during one of our most important weeks of the year.

We don't yet know how Dementia Awareness Week 2021 will look. Of course we hope to be returning to 'normal' with a wide range of networking & learning opportunities and community events. However, we learnt a lot about the level of impact we could achieve given the limitations we faced this year. Despite the effect coronavirus has had on our community, our supporters blew us away with how engaged you were in the week - thank you. Taking our learnings from this year alongside the successes of previous years we're sure we will turn Dementia Awareness Week 2021 into the biggest, most innovative and collaborative week yet.

The impact of a global pandemic

By Marri Welsh, Head of Communications and Campaigns, Alzheimer Scotland

The start of a new year usually comes with such promise. New goals are set, plans are made to fill the year and there is a feeling of optimism in the air. This is never any different for Alzheimer Scotland and, especially in 2020, we felt an incredible sense of vigour for the year ahead. We had ambitions to grow Dementia Awareness Week, plans for a long-lasting 40th anniversary celebration and the launch of many exciting new projects to focus on – as well as concentrating on continuing to provide high-quality support throughout Scotland.

And then coronavirus came.

Our main priority throughout the pandemic has always been the health, safety and wellbeing of people with dementia, carers and families as well as our staff and volunteers. We initially increased our cleaning regimes in all our local Dementia Resource Centres and local services and, in addition to this, each member of our staff monitored their temperature every day. Then, when the UK and Scottish Governments announced lockdown, we closed all of our Dementia Resource Centres, offices and services. We changed much of our support to give people the very best chance of staying connected and this included:

- Moving many of our physical groups and activities online or through telephone support
- Providing one-to-one home support in some areas, as an alternative option for some people who used our day services
- Increasing the number of staff supporting our frontline volunteers on our 24 hour Freephone Dementia Helpline.

Our Helpline, Dementia Advisors, Link Workers, Community Activities Organisers and local support teams continued to support thousands of people every day throughout lockdown. The plans we had been making to develop better online

support and digital connectivity were rolled out in a matter of weeks, helping many people keep connected. Our colleagues in every locality went out of their way to make sure the people who come to our Centres, groups and activities were still able to access meaningful therapeutic support. Although not always perfect, we know that this went some way in filling the gap.

We also focused our attention in understanding the key questions or concerns that people with dementia and their families had during such an unsettling time. We used these to create a coronavirus information hub, which you can read about on the next page.

Vitally during the pandemic we continued to plan for the future and the day we could safely reopen our support.



The new normal

At the time of reading, we should successfully be implementing a phased approach to reopening our Day Services. This will be done on a small scale and we must be cautious; ensuring extremely high qualities of health, safety and hygiene are applied at all times. We'll also be planning for a small number of outdoor activities with a reduced number of participants, such as gardening and allotment groups, which could take place using public health guidance. In our Dementia Resource Centres which do not have registered day services, we are planning to deliver safe indoor activities, again for smaller groups of people and the local teams are in the process of scoping these out too. All of our work will start on a small scale and will hopefully be able to grow. We will also continue our digital groups and you can hear more about the impact of our digital work on p28.

There is no doubt that coronavirus has been catastrophic but we hope that, as you're reading this, we are in the beginning of our new normal and are able to bring in a new decade doing what we do best: making sure nobody faces dementia alone.

If you'd like to know what support is available to you, visit www.alzscot.org or call our 24 hour Freephone Dementia Helpline on 0808 808 3000.

Coronavirus information hub

By Dawn Ferguson, Content Manager, Alzheimer Scotland

Providing access to high-quality information is an essential way for Alzheimer Scotland to support people with dementia, their carers and families. During the coronavirus pandemic, our Helpline experienced an increase in calls and our Helpline volunteers began to see a pattern in some of the topics that were being covered. Due to this, we worked with a range of internal and external colleagues to create a **coronavirus information hub** on our website, addressing some of the key themes from the Helpline. Colleagues including our Dementia Advisors, Community Activities Organisers and our Allied Health Professionals also created leaflets and videos showing activities that can be taken part in at home, both during the pandemic and afterwards.

On the Coronavirus Information Hub, you can find:

Supporting phased family visiting in care homes

The information hub has a full section regarding care homes, which is being regularly updated. This podcast talks about the best ways to reintroduce family visiting whilst following all of the care home guidance.



Staying connected

The Scottish Dementia Working Group came together to talk through some of the ways they stayed connected and active during the pandemic.

Eating well

Susan Holland, Dementia Nurse Consultant and Dr Margaret Brown from Alzheimer Scotland Centre for Policy and Practice discussed ideas around a good diet and appetite.

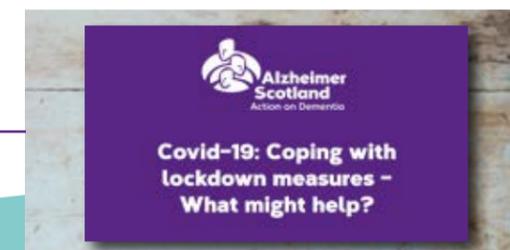


Physical activity at home

Our AHP colleagues recorded a podcast to discuss ways in which people with dementia could remain physically active at home.

Coping with stress

We know that coronavirus and the lockdown measures had a significant impact on the lives of people with dementia and their families. This podcast gives some hints and tips around this subject.



Whilst some of these podcasts and leaflets were designed with lockdown in mind, much of the information will be helpful moving forwards. To access the suite of materials visit www.alzscot.org/information-during-coronavirus. Alternatively, for information and emotional support call our 24 hour Freephone Dementia Helpline: 0808 808 3000.

Support from our localities during a pandemic

On any one day across Scotland's 21 localities you might find our Dementia Resource Centres hosting a carers support group, musical memories, a one-to-one meeting with a Dementia Advisor or a Day Care session. As well as this, our local teams work hard in the community to raise awareness of dementia. The pandemic understandably stopped the majority of our face-to-face support but, as always, our local teams have gotten creative and continued to provide high-quality, person-centred support via other means. In the next few pages, you can read just a few of the various ways we've been there for people with dementia, their carers and families throughout the country.

Cup o' kindness

By Anne O'Donnell, Community Activities Organiser, Alzheimer Scotland

During Dementia Awareness Week we wanted to deliver something extra special for the people we support, with the main aim to lift their spirits during lockdown. As no-one could come to us for a tea & a blether, we wanted to take the tea to them and decided to create cup o' kindness packs.

The name cup o' kindness is from the lyrics of the Robert Burns song Auld Lang Syne "we'll take a cup o' kindness yet" which refers to the tradition of raising a glass and meaning "good will, friendship and kind regard." I felt it encapsulated what we were trying to do, reminding everyone that they had not been forgotten by Alzheimer Scotland.

The contents of the pack included home baking, a purple picky pack, a heart box of chocolates and a

little bag of happiness. We even included tea bags and coffee sachets for their cuppa. One of our carers, Mary McShane, handmade some lovely cards and we had some wonderful donations from the local community.

Everyone showed such generosity and put the kindness into our cup o' kindness packs! We delivered 93 cup o' kindness tea & treat packs and received some lovely comments from those who received one.

"Have been reduced to tears for the first time since the beginning of this trying time. Such a lovely surprise and gesture. Will now put the kettle on and thank you for your kindness."

We're so glad that we could put a smile on people's faces during what was quite a difficult time for many.



Home support in the Western Isles

By Christine MacLeod, Daycare Organiser, Alzheimer Scotland

When the day came that we were able to do a limited amount of home support, the team in the Western Isles had a huge amount of enthusiasm. I had really positive experience supporting a lady, Murdina, who normally attends the Day Centre three times a week.

On my first visit, wearing full PPE, Murdina and I had a virtual activity scheduled called French Lingo. On arriving at Murdina's house her face lit up when she saw me and her welcome was worth all the difficult times prior. She recognised me and said she was so glad I came as she was missing seeing people. The French Lingo was explained to her and she immediately quoted a couple of French sentences!



The activity was a success and Murdina interacted well. She is a retired teacher and I could see her teacher mode at times; the session brought much laughter to us both. The next session was Musical Memories which went equally as well with lots of singing along. Murdina's carer and son have expressed how the visits have helped her and brighten her day.

After the virtual activity, we have a cup of coffee and a chat about anything: from reminiscing to the bird activity in her garden. The longer I'm in the house and the more Murdina talks, the more I can see her mind engaging and her communication improves. This home support has been a positive experience for Murdina and myself as we have built up a good rapport and are very relaxed in each other's company.

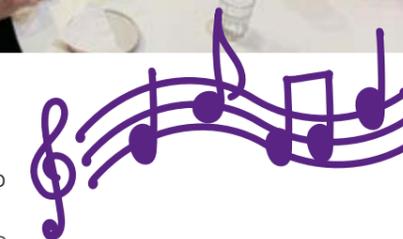
Sounding Good – Feeling Good

By John Gray, Community Activities Organiser, Alzheimer Scotland

Everyone knows about the healing power of music. It can reduce anxiety & depression and help with speech & memory. The human voice is the most effective sound-healing instrument of all.

To this end many of the activities organised by the Kilmarnock Dementia Resource Centre involve music and, in 2019, we decided to add another string to our bow. This came in the form of Kate Barbour, who runs 'Sing Like a Lark' vocal coaching sessions. Kate is a native of the Czech Republic and has lived in Scotland since 2013. She is a trained singer and vocal coach and is currently studying for a diploma with the *British Academy of Sound Therapy*.

Kate developed a workshop for a small group who we thought would enjoy and benefit from the class. Each class involves breathing and vocal exercises, singing in harmony alongside humming and 'sound baths' (the use of therapeutic sound along with sounds from nature which slow down the brain waves, stimulate deep breathing and help relax the body and nervous system). Kate has also introduced Body Percussion (BAPNE method), to the group. This exercise helps



aid memory and co-ordination for older people. The effect on the group has been dramatic; building confidence and friendships along with providing tremendous fun and laughter. Each session ends with a group lunch – next to singing, eating together is the best way to form relationships.

This of course all stopped with lockdown. However, we moved the group online and now meet up every week via the internet. It hasn't been a seamless transition but with Kate's skills and perseverance and the group's enthusiasm we have managed to get a working model that bring us most of the benefits of the class.

A digital tea and blether

By Carol Hamilton, Community Activities Organiser, Alzheimer Scotland

During the lockdown we moved our weekly Tea & Blether informal social group onto a digital platform called GoToMeeting.

Meeting online can be daunting for people who are not used to communicating digitally, and perhaps even more so if a person has dementia. To allay people's anxiety, I first invite each participant to a one-to-one session in the GoToMeeting room. In this way, I can help them to work around any technology issues they might encounter, answer any questions or concerns, and start to develop a relationship so they feel more comfortable to join the group.

Integrating members can be challenging at times as some people can be more forthcoming than others. I am mindful of those who are quieter or at a more advanced stage of their dementia journey and encourage them to chat and interact more. I



also take care to ensure the type and complexity of the activity is suitable for everyone. The current group enjoy quizzes, singing and reminiscence and provide each other with fantastic peer support, as well as lots of laughs. This helps to prevent social isolation and improve their emotional wellbeing.

"I look forward to a Friday so I can put the world to rights."

We also know that the benefits of therapeutic activities for people with dementia outlast the duration of the activity, with carers reporting that their loved one has experienced improved mood and communication after taking part in the group.

Stories we tell

By Michael Huddleston, Dementia Advisor, Alzheimer Scotland



“This has brought me out and given me something to look forward. I feel so different. I don't think about dementia. When you come here it brings it out of you – you remember there's more to you than that.”

I met Dougie Mackay, an Edinburgh-based professional storyteller, at a woodland group for people living with dementia that Alzheimer Scotland helped to facilitate in Winter 2018. As part of the session, while we warmed our hands over the fire, Dougie told a traditional folk story. I observed then how captivated people were and how they hung on every word. From here, Dougie and I discussed how we could start a creative storytelling programme for people living with dementia as the benefits were really apparent.

We applied to The Lens, which is an intrapreneurship programme geared towards staff in organisations and charities, and were fortunate enough to be chosen to take part in the process. Over numerous meetings with our Lens mentors and fellow intrapreneurs we refined our idea and honed our eventual pitch, which we delivered at the Lens Final on 16 May 2019, at the Pleasance Theatre in Edinburgh. We were awarded enough money to be able to deliver an eight week programme and write up a guide that would enable other Alzheimer Scotland staff to do likewise.

We spent the next few months fleshing out the programme, developing our criteria, referral and evaluation forms, and promotional material. By October 2019, we were ready to go and had seven participants for our first group. For each of the following eight Tuesdays we introduced different creative stimuli to encourage participants to share their stories; be them biographical, fantastical, or a mix of the two. We heard

some amazing stories – about one man's escapades with a Bulgarian bear, a Spanish lady's Junta-era research in a ransacked Argentine library, and a Hearts supporter's adventures in post-apocalyptic Chernobyl, as well as many more besides. Most of the sessions began with the group together, then split into two smaller groups, where anecdotes and ideas were turned into stories and poems. We collated the best of this work – long and short form – in a collection that we presented to the participants at an additional celebration session a few weeks after the programme had concluded. We took this opportunity to reflect with participants on their experience of Stories We Tell. The feedback we heard was at points profound, always humbling, and far exceeded our expectations. We captured a transcript of participants' reflections and have set this alongside feedback we sought from carers after each session, as well as our own

thoughts, observations and learning in an evaluation document. Using everything we learned from the programme we will now write up a Stories We Tell resource. One thing we have learned is that there is some alchemy between the resource and the delivery that makes the programme truly meaningful. For this reason, we are looking to develop a “train the facilitator” and mentoring package that will help embed Stories We Tell across the organisation; supporting staff to develop the skills and confidence to deliver the programme. Once this becomes part of the range of innovative therapeutic activities offered by Alzheimer Scotland we hope the resource can be scaled further, becoming an idea and product that can be marketed to other individuals, groups and organisations that would benefit from the demonstrable impact the programme has had to date.

“It's given me motivation to go and do things again. Before I came here, I hadn't been doing any drawing or painting but now I go and sit at the desk every day and try and do something.”



The Season's Change

This time of the year is beautiful for an artist:
Nature's own pyrotechnics; a profusion
that masks winter's loss
But a peculiar absence of blue.
Still warm sunshine
We begin to gather in, ready
for the months ahead
For the white and grey to come.
The sky glows with the persistence of the season;
Russet, orange, gold.

Eric Bee

Eric George James Bee
Had a habit of climbing up trees
With friends he went scrumpling
From a branch he'd go jumping
Landing with beautiful ease



Helpline Reflections

By Jennifer Hall, Helpline Manager, Alzheimer Scotland

When the coronavirus pandemic hit, I had many questions in my head: what would this mean for the people of Scotland? Crucially, what would this mean for over 90,000 people living with dementia and their carers across Scotland? By early March calls to our 24 hour Freephone Dementia Helpline were coming in quickly, and most of them related to the pandemic. Almost overnight our Helpline became central to supporting people with dementia and their families through this crisis. The calls to the Helpline allowed us to capture the key issues people were experiencing and feed this back to the Scottish Government. The guidance being issued nationally was coming out quickly, and we played a key role in translating what it meant specifically for our dementia community.

Our incredible team of highly trained volunteers are there to answer your calls 24/7. Almost instantaneously we needed to adapt and evolve by going digital so we could continue to reach people during lockdown. Much time was spent by volunteers as we tried to figure all this out together from the isolation of our own homes. This came with challenges, however the dedication and tenacity of our volunteers to be there for our callers meant we persevered and found a way.

Year on year, we experienced a **30% increase in calls** and the average call time increased by an astonishing

80%



For 40 years Alzheimer Scotland has been there for people to ensure that no one goes through dementia alone. In the last 6 months we have worked tirelessly to maintain this, with feedback from our callers telling us our Helpline has been a lifeline for them makes all of the challenges worthwhile.

Laura Porteous, Alzheimer Scotland's Trusts and Foundation Manager, shares her experience of volunteering on the Helpline during lockdown:

My new normal Monday morning. A call from a concerned daughter whose mother went into a care home as a trial before lockdown. Now she has been forced to remain in the care home and her daughter hasn't seen her in weeks. A second call is from a man who has been helping his neighbour and has become concerned as she no longer seems to recognise him when he comes to the door with her shopping. A third call. A daughter who simply can't cope being her mum's main carer with her calling at all hours of the morning saying someone is in the house. Her carers have stopped coming since coronavirus, leaving the daughter even more concerned. It has even led to family fallouts with her sister, who doesn't live in the area. My first shift was overwhelming and each call was totally different from the next. It was sobering to hear the problems families living with dementia were facing.

The experience has been so invaluable to me over the past few months. It was very hard to hear about so many challenging situations that people have found themselves in due to coronavirus but being able to provide them with information, emotional support and pass them on to our expert staff restored a sense of hope for me. As someone who writes funding and grant applications, it has enriched my ability to talk to funders about our work, the people we support and our amazing volunteers. It really hit home to me that our Helpline is a lifeline to families, especially during difficult times.



The two Rons

By Wendy Rankin, Dementia Advisor, Alzheimer Scotland

When lockdown commenced in March 2020, no-one could have predicted how things would have turned out. Ronald Adam was a regular attendee at the Monday drop in cafe, where he enjoyed a game of pool and a bit of banter with the regulars, and the group of men were supported by volunteer Ron Byer. Following lockdown, and the suspension of the various cafes, groups and activities, Alzheimer Scotland began to match up volunteers and the people we support with telephone befriending. The "two Rons" were matched together as they already had a relationship, and this has continued to thrive. Below, both Rons talk more about the friendship that has blossomed:

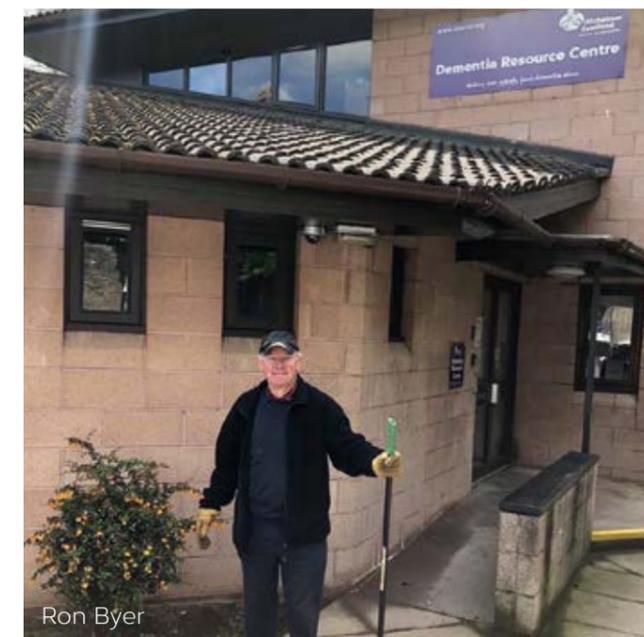
Ron Adam

I was diagnosed with dementia three years ago and, for two of those years, I have attended the Dundee Dementia Resource Centre. Initially I went along with my late wife - we both got different types of support. When she died, I continued to go most Monday, Thursday and Fridays - the people in the Centre are great company and have been a real support to me. What you see is what you get with me and I enjoy the banter that comes with being around everyone at the groups.

Ron the volunteer was the very first person to sit down next to me when I started going back to the Centre after my wife died. He had gone through the exact same thing and it was good to speak to someone who knew what I was going through - we had a long chat about our experiences. I found lockdown really difficult; it's been hard not getting out and seeing everyone but my daughter, Gail, has been brilliant. Not being able to go to the Centre has left a big hole in my life but I know we've all been in the same boat in having to stay at home. I've been grateful to Ron, who I class as a friend now. He still phones me every week for a catch up and some good chat - we rub off on each other.



Ron Adam



Ron Byer

Ron Byer

I've been a volunteer for Alzheimer Scotland for about two years. My late wife had dementia and it was really important to me that I gave something back but, more than that, I also wanted to do something which helped fill my time after she died.

Prior to the lockdown, I was volunteering at the Dundee Dementia Resource Centre three times a week, including on a Monday at the drop in café. My Monday volunteering slot would usually include chatting to the men who attended and playing pool; it's such a friendly atmosphere anyway but I really enjoy getting to know everyone. I have struck up a great friendship with many of the attendees but particularly with Ron Adam - we clicked straight away and have very similar opinions and interests. During lockdown, I was still keen to help in any way I could. I live two minutes from the Centre so, when I was able to, I walked past as part of my daily exercise to make sure the building was ok from the outside. I also began companion calls with Ron; I phone him every Monday for a chat, usually for about half an hour. We talk about anything, we both read the local newspaper so sometimes we'll discuss what we've read in the news or we'll talk about football.

I know Ron struggles with not being in the Centre and sometimes I can hear he's down about it. I feel my role is to let him talk about how he feels and hopefully, naturally, I can help lift his mood. I really enjoy volunteering with Alzheimer Scotland and meeting people like Ron; it has definitely helped me feel like I'm giving back to my community.

The voice of our community

By Gillian Councill, Locality Leader, Alzheimer Scotland

Throughout history, creative writing has been used to capture time and human experiences, as well as act as a therapeutic channel for reader and writer alike. To truly understand what people are experiencing, you need a window into their lives, and this collection of short stories and poems are intended to serve that purpose. They convey some of the themes, challenges and moral dilemmas people are faced with every day. The stories are all based on real experiences but have been anonymised for confidentiality reasons.

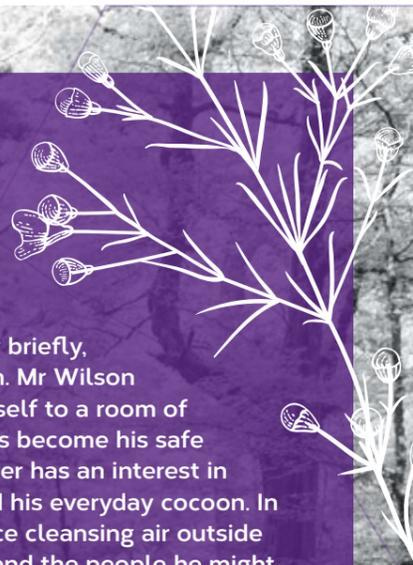
Mr Wilson was an adventurer. He could often be found exploring local woodlands and hill tops, on foot or by bike; a get up and go kind of guy. Despite Mr Wilson's diagnosis of dementia, his inner explorer always prevailed.

Sometimes it got him in trouble with his wife, he'd often go for too long or go too far. Mr Wilson was a gentleman who was always dressed for the weather, like he was prepared for whatever the Scottish elements had to throw at him. He was very in tune with the natural world around him; being outside was how he got his energy; the fresh air ignited his mind and the environment inspired him. His wife would always notice her husband was brighter, more animated, more engaging after a day of being out on an adventure. Being outside was a social experience for Mr Wilson too, he would often talk with people when he was out and about, exchanging stories and tales about the local area. This was a topic that Mr Wilson was comfortable with, he had knowledge to share and it made him feel good. I suppose when someone has dementia, nature is a safe place, it doesn't judge or expect you to follow etiquette; it just lets you be.

There has been a change in Mr Wilson since the start of this pandemic and all the changes to everyday life that have occurred on its account. Mr Wilson's world has shrunk. That once inquisitive man no longer wonders what marvels lie beyond his garden gate.

Mr Wilson has been at home since the start of lockdown and has rarely stepped out of his house, even if he does, it is only briefly, and to the garden. Mr Wilson has resigned himself to a room of his house that has become his safe place. He no longer has an interest in the world beyond his everyday cocoon. In his mind, that once cleansing air outside is contaminated and the people he might meet are to be avoided at all costs. Mrs Wilson has gone from struggling to keep her husband in, to being unable to convince him to leave the house. He is no bother to his wife; he eats and drinks, responds appropriately when addressed and follows household routines as best he can. The significant change is that Mr Wilson is flat, lifeless; he's lost his imagination. Mrs Wilson often finds him in a vacant trance like state, appearing withdrawn and disinterested. His conversation has become menial and he doesn't ask questions anymore; like what breed of bird is that on the feeder? Or I wonder how fast I could walk the circuit in the woods near the house? Would you describe this man as someone in distress? Does he feel apathy or social pain? Whatever the reason, he is a man feeling disconnected from the world that once invigorated him, becoming increasingly afraid of re-entering it.

It's as though his already fragile mind has gone into power saving mode. Taking what it needs from its surrounds to survive and no more.



Jane was like a fine china teacup; dainty, delicate, elegant, yet full-bodied and strong inside. Drinking tea with friends was a weekly ritual. Jane, Jessie, Mable and Annie have been meeting at the same café, at the same time and day each week for the last 20 years.



It's a Friday morning and Jane gets ready for her café date as she always does. A little dusting of powder to the cheeks, a splash of rouge to the lips and a good coating of lacquer to the hair. Jane often wears her smart coat for the occasion and doesn't leave the house without a splash of Channel Number 5. Jane leaves the house in plenty of time and makes her way to a nearby bus stop to catch the number 27 to town. The bus arrives on time, Jane flashes her bus pass at the driver and takes a seat. Finding a seat is surprisingly easy today as the entire bus is empty. 'Quiet today' Jane mutters to the bus driver. Jane is slightly perplexed by the lack of people on the bus but concludes that it must be a bank holiday or something like that. Jane gets off the bus at her usual stop and thanks the driver who rather oddly says 'you stay safe now'; that's very caring indeed, Jane thought to herself. The 5-minute walk from the bus stop to the café is noticeably quiet too, there are very few people around. In some ways Jane finds the lack of crowds quite nice, not having to dodge in and out of people. Jane being dainty means that she can feel quite vulnerable in big crowds. Whilst walking to the café, Jane is starting to get excited about seeing her friends and thinks of what they might talk about. Mostly, they talk about the 'good old days' and all the fun times they've had together as friends. Talking about old memories with her friends is one of Jane's favourite things to do and she can participate, instead of

trying to remember what she did since last week; that doesn't always come so easy. Jane arrives at the café and wonders why it looks so dark inside, maybe they've had a power cut, she wonders. She goes to open the door to find it locked. Jane rattles the handle to no avail. Peering through the glass door she can see no-one inside and then notices a sign on the door that reads:

"To all our loyal customers, it is with heavy heart that we are closing our business until further notice due to coronavirus. We hope to reopen in the future and thank you for your support over the years - stay safe"

Coronavirus, what on earth is that, thinks Jane? It sounds vaguely familiar. Jane wonders if her friends have already been and gone, or maybe they knew it was closed already, they could have told me. Jane takes a moment to recover from her feeling of deep discontent, mostly because she won't get to see her friends and chat over tea and a scone; her favourite time of the week. Jane begins the lonely journey back; she has a long wait at the bus stop but eventually makes it home. Usually Jane returns on a Friday feeling happy and content, but not today. Today Jane feels sad, lonely and really miffed, especially by this Coronavirus business. Never mind she thinks, we'll try again next week.

Jane has made that same journey every single Friday since the start of lockdown, each week is the same, she finds an empty café and no sign of her dear friends.

It is our pleasure to share your story and help have your voice heard. If you would like to explore ways to do this contact Dawn Ferguson, Content Manager by email: dferguson@alzscot.org or by phone: 0141 410 0108.

Lockdown with dementia

By Danny and Catherine McDonald

Danny:

"I was diagnosed with vascular dementia in August 2016, aged 51. The diagnosis itself was hard to come to terms with and it has taken some time to accept. Even now I can sometimes become overwhelmed; not just with how dementia affects me but how it affects my family too.

I began attending Alzheimer Scotland's day care in Clydebank in November 2018. I was originally quite apprehensive when a place became available for me one day a week, however I don't know what I was worried about! I really enjoy the day care, so much so that I now attend two days a week in normal circumstances. I've met a lot of friends there and there are lots of activities to take part in – plus great banter with the other attendees. It's become a constant form of support in mine and my family's life.

I was devastated when I found out that the day care was closed. I was really worried that my dementia would deteriorate due to the lack of socialisation and stimulation. Initially I was ok being at home and happy to receive the activity packs that Laura, the Community Activities Organiser at Alzheimer Scotland, sent. I also received a weekly call where we would do a short quiz and it was something I looked forward to. However, as time went on I became a bit depressed. Due to the medication I'm on, I was classed as being in the 12-week shielding category which meant I had to isolate. I spent most of my time in bed and my appetite changed; I was really struggling to adapt. Linda Buchanan from the day care was brilliant – she was really encouraging and suggested

increasing my weekly calls to twice a week. She also asked me if there was anything of interest she could get for me – I asked for an 80s rock band quiz as I'm a Status Quo fan and went to some of their concerts. She came back with an amazing quiz which was something I was able to complete with my wife Catherine and my kids. Speaking with Linda also gave me motivation to get out of bed, complete a word search and learn a new tune on my ukulele.

There have been points during lockdown where I have found it really difficult – I caught an infection and there were a couple of weeks where I didn't feel up to interacting with anyone. I stopped attending Scottish Dementia Working Group meetings and struggled to interact with my family. However the team at the Clydebank Dementia Resource Centre have been there all the way. They've offered support to myself and my family and gently suggested activities that I might enjoy. I've now begun to regularly attend online groups where we chat with other people who have dementia, their families and staff. It's helped me feel back to normal and I'm glad if I can have a joke and make other people laugh!



Catherine:

"Our family have been really reliant on the support that Alzheimer Scotland offers for some time now. Both Danny and I are members of the two respective campaigning groups, Scottish Dementia Working Group and National Dementia Carers Action Network and we get wonderful support from our local Dementia Resource Centre. Lockdown, and the lack of face-to-face support was really hard on Danny, but we never felt alone. After one of the interactions Danny had over the phone, he was more enthusiastic and motivated than I'd seen him in some time – I don't know what was said in that phone call but it really helped!

A few weeks into lockdown Danny became quite confused and agitated and was diagnosed with

an infection. At this stage Danny struggled to recognise me or our two grown up children. He reverted back to a time in his life when he was 22 years old and newly married, when in fact we had just celebrated our 34th wedding anniversary. Danny also thought he still worked for the buses – he'd woken up in the early hours thinking he had missed a shift and was constantly trying to find his uniform.

The infection did take its toll and Danny definitely regressed; he didn't want to speak to anyone at all. As he was shielding, we couldn't receive any home support so it was a lifesaver when we were told about one of Alzheimer Scotland's digital groups. It took some convincing but

we joined the group and as soon as Danny heard and saw familiar voices and faces he was able to relate to who they were. He even sang "We'll Meet Again" along with others before taking part in a quiz and he stayed on the call with everyone for about 45 minutes. Danny seemed more like himself, smiling throughout and laughing and joking with everyone and I really noticed his demeanour became more relaxed. The groups have been ongoing weekly now and we both really look forward to them.

It has been a rollercoaster of a time; we've had every emotion possible but we are so thankful to Alzheimer Scotland who have been by our family's side. Even during the hardest of times they've known what to do or how to help and it's made all the difference.



If you are interested in any of Alzheimer Scotland's groups or activities, please visit www.alzscot.org or email info@alzscot.org to be put in touch with your local Dementia Resource Centre.

If you are interested in becoming a member of either Scottish Dementia Working Group or the National Dementia Carers Action Network, please contact Caroline Russell by email: crussell@alzscot.org or by phone: 0141 410 1171.



Alzheimer Scotland are dedicated to making sure nobody faces dementia alone. Here are some of the ways you can contact us.

Email: info@alzscot.org

Web: www.alzscot.org

Our 24 hour Freephone Dementia Helpline:

0808 808 3000

 @alzheimerscotland
  @alzscot
  @alzscot

Making sure nobody faces dementia alone.

Reflections on 40 years of the Alzheimer movement in Scotland

David McClements, Convener, Alzheimer Scotland

This year marks the 40th anniversary of the Alzheimer movement in Scotland. In 1980 Glenda Watt, a nursing sister at the Royal Edinburgh Hospital, arranged a meeting of interested professionals and concerned carers to address what was needed to support carers and provide information to them about the effects of Alzheimer Disease. As a consequence of this meeting the Edinburgh Branch of the Alzheimer's Disease Society was established in May 1981 and hence set in motion the developments and organisations (including Alzheimer Scotland) which were to follow.

Most care at that time was provided in hospitals and at that initial meeting there was a determined attitude from those present that they should act as a pressure group to effect changes in the grossly inadequate caring facilities. Although much has changed for the better in the ensuing years, it remains a key objective of Alzheimer Scotland to ensure the best standards of care and support for people living with dementia are maintained. In those early years the services provided were entirely maintained by volunteers including Drop In and Home Support in the form of a sitting service as well as the fundraising necessary to allow the work to continue. However it was as part of a branch of the Alzheimer's Disease Society and so, in 1987, the members in Scotland voted to form their own organisation - Alzheimer's Scotland, and appointed their first Executive Director - Ewan Davidson. He has been followed by only two other Chief Executives, Jim Jackson and now Henry Simmons. The organisation has derived much of its strength and influence within our society by the excellence of its leadership. They have all ensured the organisation adapted to changing needs and encouraged innovation in the way services and support have been delivered.

There have been too many volunteers involved to mention them all but people like Maureen Rasbash, Evelyn McPake and Alison Glen were among those who had the foresight to establish Alzheimer Scotland. Scotland had always had its own health and social care system and the organisation needed to ensure it was able to respond most appropriately from a Scottish perspective. Campaigning has always been at the heart of what is done. Some may remember the GLAD (Getting Local Action on Dementia) Campaign from the early 1990s which sought to empower people in their own communities to effect change to suit the needs of their area. We still recognise the importance of this local action in our strategy for localities as we move into our fifth decade.

I am also very conscious of the importance in the dementia field in Scotland of the merger in 1994 of Alzheimer's Scotland with Scottish Action on Dementia.

This created a single organisation to support people living with dementia and provide information to carers, raise funds for the aims and objectives and campaign for policy change. Campaigning for policy change was aided by the work of the Helpline, which last year celebrated its 30th birthday. It has been available to support carers 24/7 for many years and as a result has been able to glean an intelligence from its conversations with people about problems with services and with legal arrangements that aided those seeking policy change. Through the years our policy reports have been significant in setting the agenda and creating the environment for change in Scotland. In the late 1990s this meant the organisation was at the forefront of the national campaign to change our incapacity laws which were by then a long overdue reform. Thanks to the determination of many and the policy reform campaign led by Alzheimer Scotland - Action on Dementia, the Scottish Parliament enacted its first major piece of legislation - The Adults with Incapacity (Scotland) Act 2000.

I believe Alzheimer Scotland, which seeks to represent and campaign for people living with dementia and their carers, has made its mark internationally too. Other countries have observed and been impressed by innovations in Scotland often through our connections with Alzheimer Disease International and Alzheimer Europe. Scotland was proud to host an ADI conference in Edinburgh in 1994 when over 500 people attended from other countries. However in more recent years this admiration has been most exemplified by the establishment of the Scottish Dementia Working Group to ensure people living with dementia had a forum to voice their own concerns and demands for change. This has now been replicated in other countries worldwide.

A few years ago Henry Simmons said at our annual conference that what is achieved now has happened because we stand on the shoulders of the giants who preceded us and laid the foundations and the ethos for what is done today. I wholeheartedly agree with this sentiment as we continue with our vital work into our fifth decade.



Decade by decade: the history of Alzheimer Scotland

By Dawn Ferguson, Content Manager, Alzheimer Scotland

Since 1980 Alzheimer Scotland, and the previous iterations of the charity, have been helping to make sure nobody faces dementia alone. It is quite staggering to see how the charity has evolved which is, in part, down to the many staff, volunteers and trustees past and present who have been committed to its growth. As the decades have progressed, so have our priorities and we now live in a world where the person is at the heart of all we do.



1980s

The very beginning

Scotland's part in the Alzheimer story begins in 1980 when Glenda Watt, a sister at Ward 5 of the Royal Edinburgh Hospital, read an article by Cora Phillips in the Nursing Times and made contact with her. Cora Phillips had initiated the Alzheimer's Disease Society in England. Glenda had already seen the need for a method of encouraging and informing the relatives of people living with dementia and was running a support group for carers and families in the hospital. This gave her a base from which to proceed and the committee in London invited her to become the Scottish representative. Glenda arranged a meeting which took place in Ward 5 on a Saturday afternoon in 1980. Approximately 30 people attended, and were treated to a series of talks by a number of professionals in the field of dementia, explaining the ways in which they could assist the person with dementia and their carers. This was the very beginning of what became the Edinburgh Branch of the Alzheimer's Disease Society, and then Alzheimer's Scotland in 1987.



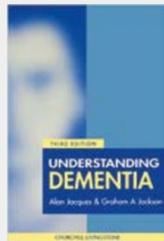
Alzheimer Scotland's Helpline

Alzheimer Scotland's Freephone Dementia Helpline was first introduced in 1989. Initially there were periods of time where the Helpline couldn't be staffed however, in 1991, funding became available to make it the UK's first 24 hour Freephone Dementia Helpline. It continues to operate by a group of skilled and dedicated volunteers 24 hours a day, 7 days a week. Since records began, the Helpline has answered over 118,000 calls from all across the world. Our volunteers are there to provide information, emotional support and often just a listening ear. They're regularly the first point of contact for people worried about their memory, people with dementia, carers, family members, friends and professionals.

Also in this decade

- The very first Newsletter was published
- First Scottish conference on dementia was hosted
- First two projects set up in Paisley, a Day Care, and Kirkcaldy, a Respite Centre
- Scottish Action on Dementia was established
- The first Dementia Awareness Week was launched
- Dementia Services Development Centre was established

- First training officer appointed
- 'Understanding Dementia' was written by Alan Jacques and Graham Jackson, which is one of the earliest texts on dementia that helped us understand the experience of dementia



First Newsletter published

1990s

The merging of two organisations

In 1994, Alzheimer's Scotland and Scottish Action on Dementia merged to become the charity it is today: Alzheimer Scotland - Action on Dementia. Both organisations, along with the Dementia Services Development Centre, had clearly identified roles and remits and worked closely together, however natural public confusion and overlap of work led to the amalgamation. The success of Alzheimer's Scotland and its predecessors was based on the commitment and enthusiasm of the early pioneers, followed by its effective transformation into a fully professional organisation. Scottish Action on Dementia worked because it embodied so successfully the principle of collaboration between all those involved in dementia care. The aims of both organisations were combined and continue to be carried forward:

- to be the national and local voice of and for people with dementia and their carers in Scotland
- to improve public policies for the benefit of people with dementia and their carers in Scotland
- to provide and secure the provision of high quality services for people with dementia and their carers in Scotland.

International Conference and World Alzheimer's Day

Scotland's involvement in the international aspect of the Alzheimer movement began with attendance at the third Alzheimer's Disease International (ADI) conference in Paris in 1986 and our presence there laid the groundwork for our eventual independent position in the international organisation. A landmark was met when the 10th conference of Alzheimer's Disease International was held in Edinburgh on 21-23 September 1994 with over 800 delegates from 38 countries. The conference, under the practised leadership of Brian Moss from Australia, then Chairman of Alzheimer's Disease International, was voted an outstanding success and is still fondly remembered by those from all over the world who attended. Princess Yasmin Aga Khan (President of Alzheimer's Disease International and daughter of film actress Rita Hayworth who had Alzheimer's disease) gave the opening address. At this conference, the first World Alzheimer's Day was declared between ADI and the World Health Association.



Also in this decade

- The Woodlands Centre in Inverness, the second purpose-built Day Centre in Scotland was opened
- Inaugural Dementia in Scotland magazine
- The first service in Scotland for younger people with dementia was launched
- A successful campaign for people with dementia to be exempt from Poll Tax
- The Scottish launch of the international research campaign, Race Against Time
- A campaign to ensure married carers had rights to their husband or wife's occupational pension should they go into long-term care was successful
- Our fundraising efforts grew over the decade including an annual West Highland Way walk, fashion shows and forget-me-not appeal
- First young onset dementia conference held
- Local campaigning groups which met in the evenings called GLAD groups - Getting Local Action on Dementia - were created

2000s

Charter of Rights for People with Dementia and their Carers

In 2009, we worked with the Scottish Parliament's Cross Party Group on Alzheimer's and the Scottish Human Rights Commission to create the Charter of Rights for People with Dementia and their Carers in Scotland. The Charter places their human and other legal rights at the centre of Scotland's National Dementia Strategies.

It underpins both the Standards of Care for Dementia in Scotland and Promoting Excellence: an education framework. Both are key commitments of Scotland's National Dementia Strategies to deliver the highest quality of care, treatment and support for all people with dementia in Scotland.



Also in this decade

- Free Personal and Nursing Care was introduced
- First Dementia Resource Centre in Oxford Street, Glasgow was completed
- Our supporting living accommodation at Croftspar Place, Glasgow was opened
- The Dementia Advisor post was created
- Alzheimer Scotland's 2009 dementia manifesto called for a National Dementia Strategy
- Facing Dementia Together post diagnostic pilot project was launched
- Adults with Incapacity (Scotland) Act was passed

2010s

Scotland's National Dementia Strategies

Since 2010 Scotland has introduced three national dementia strategies, published in 2010, 2013 and 2017. Alzheimer Scotland had campaigned for a National Dementia Strategy for many years and have been fully engaged as an equal partner alongside the SDWG and NDCAN, in the development, implementation and monitoring of each of the three strategies. Each strategy has helped to inform some key pieces of work:

- Alzheimer Scotland has played a vital role in driving change and improvement in health care for people with dementia. In partnership with the University of the West of Scotland and funded by the Scottish Government we have trained 1000 Dementia Champions who, supported by our Dementia Nurse Consultants, work within the NHS to act as change agents and promote best practice to improve the experience, care, treatment and outcomes for people with dementia, their families
- Alzheimer Scotland has also been supporting improvements in care through Scotland's Allied Health Professionals (AHPs) community. Together with Scotland's AHPs we have developed and rolled out Connecting People, Connecting Support: a framework for how AHPs in Scotland can improve their support for people with dementia
- A major landmark has been our role in obtaining a commitment from the Scottish Government to provide every person diagnosed with dementia, in Scotland, with a guarantee of a minimum of one year's post diagnostic support, from a named link worker, based on Alzheimer Scotland's 5 Pillar Model of Post Diagnostic Support.



Scottish Dementia Research Consortium

In 2013, Alzheimer Scotland facilitated development of the Scottish Dementia Research Consortium (SDRC) with the aim of supporting Scottish dementia research through the development and expansion of high quality, co-ordinated and collaborative research.

Scottish Dementia Research Consortium (SDRC) is a network of dementia researchers, policy-makers and people living with dementia from across Scotland. The main purpose of the SDRC is to champion the work of our world-class dementia researchers, in all disciplines, that is already taking place throughout Scotland

The SDRC is made up of around 500 members so far and is open to anyone with an interest in dementia research. The SDRC works in five themes, which encompass all aspects of dementia research ongoing in Scotland:

- Diagnosis: development of diagnostic methods for the early detection of the illnesses of dementia
- Fundamental Science: the contribution of basic science in translating promising laboratory research into the development of new drug treatments
- Living with dementia: research into interventions and approaches to the care and support people with dementia and their families
- Prevention: improving our understanding of dementia risk factors will lead to the development of treatments that can prevent or the delay of the symptoms of dementia
- Scottish Dementia Informatics Partnership: supporting the use linked health data to support research and advance treatment.



Also in this decade

- A network of jointly funded Alzheimer Scotland Dementia Nurse Consultants were formed
- The 24th annual Alzheimer Europe conference was held in Glasgow
- The Dementia Friends programme was introduced in Scotland
- The Alzheimer Scotland Centre for Policy and Practice was opened, in partnership with the University of the West of Scotland
- The National Dementia Carers Action Network was formed
- Alzheimer Scotland committed to its digital products, technology and innovations; including the first Digital Dementia Resource Centre
- The Dementia Dog Project was launched
- Alzheimer Scotland Dementia Research Centre, a partnership between Alzheimer Scotland and the University of Edinburgh, was opened
- The Advanced Dementia Practice Model was created
- Free Personal Care was extended to people under 65, thanks to Frank's Law
- Transforming Specialist Dementia Care report was published
- Alzheimer Scotland became a partner of Join Dementia Research
- The Fair Dementia Care campaign was created



It's not possible to highlight every piece of work over those 40 years but we are incredibly grateful to those past and present who have made a direct or indirect impact in the lives of people with dementia, their carers and families. In this we reflect on just some of the key work that Alzheimer Scotland has either led on, or contributed to, over 40 years.

40 years of Alzheimer Scotland

Thank you to previous and current staff, volunteers, supporters, key partners and trustees for being part of our history. Most of all, thank you to the people we support for allowing us to help make a difference to their lives and many future generations.



40 years of Alzheimer Scotland

Tackling inequalities

By Jim Pearson, Director of Policy and Research, Alzheimer Scotland

There is no doubt that the coronavirus pandemic has disproportionately impacted on people living with dementia, their families and carers. It has shone a light on the existing inequalities and gaps in our health and social care system which we have been highlighting in our Fair Dementia Care Campaign since its launch in January 2019. In the recent weeks, we have written to the Cabinet Secretary for Health and Sport, asking for urgent action to address these inequalities.

“ Over the past six months we have all been living with the impact of the global coronavirus pandemic. This virus and the measures in place to prevent it spreading have had an affect on all our lives in one way or another. For some that has meant changes to how we work, travel, socialise and much more. For others the changes to their lives have had a much greater impact. In Scotland alone thousands of people have died, a personal tragedy for them and their families. Many more have experienced a decline in their physical and mental health and wellbeing and, for people with dementia and their families & carers, this crisis has taken a terrible toll. There is clear evidence that they have been disproportionately impacted by this pandemic.

While the restrictions in place to prevent the spread of the virus were necessary to save lives, they also had unintended consequences which have become increasingly clear throughout the past few months. Alzheimer Scotland's 24 hour Freephone Dementia Helpline volunteers, local Dementia Advisors, Post Diagnostic Support Link Workers and other colleagues have supported thousands of people with dementia, their families and carers using innovative and alternative approaches. They have been hearing first-hand how this crisis, and the measures to prevent the

virus spreading, is impacting on people with dementia and carers. Sadly, too many have experienced the death of someone close to them during this crisis, often having little or no opportunity to be with them at the end of their lives or to mourn together with close friends and family.

The disruption in people's usual formal and informal support networks has also had a substantial impact. Many people with dementia have been isolated. They've been unable to see family and friends, retain their usual daily routines or participate in the activities or the support which can help keep them well for longer. Many also had their existing social care support reduced or withdrawn during the crisis. All of this has had a significant impact and there is growing evidence of substantial decline in the physical and mental health of people with dementia, increased levels of stress and distress, cognitive decline and acceleration of the progression of the dementia. We are also hearing of overwhelming levels of carer stress, with many carers reporting that they are struggling to cope. In recent weeks there also appears to be a notable increase in people with dementia moving to care homes.

Throughout this crisis Alzheimer Scotland has continued to converse with the Scottish Government to highlight the issues that people with dementia, their families and carers are telling us about. Our hope is that this relationship helps inform their response and addresses the issues that our dementia community are facing. It is increasingly evident that many of those issues are not caused by the pandemic, but by the inequalities and gaps in our system which have undermined its capacity to respond to a global pandemic of this nature.



5 pillars of PDS model

In 2019 Alzheimer Scotland launched the Fair Dementia Care Campaign with the publication of our “**Delivering Fair Dementia Care for People with Advanced Dementia**” report. The report highlighted two glaring inequities faced by people with advanced dementia, their families and carers. These are: the lack of equal access to the health and specialist nursing care people require to meet increasingly complex and changing needs that are synonymous with advanced dementia, and the inequity of having to pay for care which we rightly don't expect for those who have other progressive and terminal illnesses. For many, that may mean having to sell their homes or use up most of their life savings and incomes to pay for care fees. These inequalities have been exposed further by this current crisis, with many people either having their social care packages withdrawn or reduced during a time when it was most needed. Those living in care homes or who moved from hospital to care homes at the start of this crisis have continued to pay care home fees while being at the very frontline of the impact of this virus, isolated in their rooms and without access to the supports that care homes would normally be able to provide. We have asked the Cabinet Secretary to take urgent action to deliver Fair Dementia Care and end the inequity of people with advanced dementia having to pay for health care which should be free. Post diagnostic support performance data published in March this year shows that the number of people being offered post diagnostic support after a diagnosis has fallen. **Of the estimated 18,000 people diagnosed with dementia in 2017/18 only 7,605 were offered post diagnostic support.** High quality, person-centred support after a diagnosis can make a huge difference to ensuring that people can live well for longer

and avoid unnecessary and unscheduled hospital admission. It can also prevent people moving into a care home earlier than they may have otherwise needed to. Without this crucial support many people with dementia and their families had less opportunity to have the care and support they needed in place when this crisis began.

We have also asked the Cabinet Secretary to take urgent action to provide specific additional funding to double the number of Post Diagnostic Support Dementia Link Workers and ensure that every person who is diagnosed has the opportunity to benefit from high quality post diagnostic support that can help them live well at home.

These two asks could make a significant difference to the people that we support and we will keep you updated as our conversations progress.

Your voice is essential in helping us tackle these inequalities. We are grateful to the many people so far, including members of the Scottish Dementia Working Group and National Dementia Carers Action Network, who have told their story. If you would like to explore how you can help make a difference by sharing your experiences of living with dementia or caring for someone with dementia during this crisis, we would welcome the opportunity to speak to you. ”



If you would like to sign up to the Fair Dementia Care campaign, visit www.alzscot.org/fairdementiacare and we would appreciate you encouraging others to do likewise. If you'd like to talk about sharing your story, email info@alzscot.org or phone 0131 243 1453.

What is Brain Health Scotland?

Professor Craig Ritchie, Director, Brain Health Scotland

In recent years, strong evidence has emerged that some forms of dementia could be prevented. Launching in late 2020, Brain Health Scotland will provide expert advice, coordination and crucial contributions to a future Brain Health Strategy within Scotland. Brain Health Scotland is being delivered in partnership with the Scottish Government who are funding this collaborative initiative, which will also involve Scottish Dementia Research Consortium, Scottish Dementia Working Group, National Dementia Carers Action Network, along with other key stakeholders. Alzheimer Scotland will play a crucial role, hosting and supporting the development and implementation of Brain Health Scotland. Over the next four pages, you can find out more about this pioneering initiative.

“ What is Brain Health Scotland?

The vision for Brain Health Scotland emerged from two primary observations.

Firstly, research activity, health informatics, clinical practice and public health can only do so much individually to address any health care issue. But collectively and in a coordinated fashion the yield can be greater than the sum of the individual parts.

When it comes to brain health, it is well known that the research activity in Scotland in this domain is quite simply staggering. The latest Scottish Dementia Research Consortium Impact Report showed that, in the last five years, Scottish researchers led on £160 million pounds of research funding across our Scottish universities. Projects like European Prevention of Alzheimer's Dementia Consortium (EPAD), the Dementia Research Institute in Edinburgh, the Football's Influence on Lifelong Health and Dementia Risk (FIELD) study from Glasgow and many others serve to illustrate how Scottish researchers are at the forefront of innovation and discovery in this field. The main challenge for these researchers



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is the time taken to translate research findings into clinical practice. Brain Health Scotland will tackle this, not only by raising awareness of research findings and activity, but also by driving participation in two critical groups – NHS clinicians and the public as a whole.

Through working with and, where necessary, helping to resource projects, Brain Health Scotland will build a partnership with The Royal College of Psychiatrists, SIGN, Association of British Neurologists, British Geriatric Society, Royal College of Nursing, The Royal College of Physicians of Edinburgh, The Royal College of General Practitioners and others. We will work with sporting associations, employers and food providers to identify opportunities to impact brain health.

Together, these organisations will calculate the needs, ambitions and challenges of their respective members, to ensure that clinical practice for people at risk of dementia can undergo rapid cycles of innovation.

Secondly, there is an opportunity for the public to engage in research at much higher levels than they currently do. There is no doubt that a significant number of people living in Scotland will develop dementia in the next 10 years, yet less than 0.1% of these people will be offered the chance to participate in the research that is so crucial to help engineer a different future. This is why, with Alzheimer Scotland, Brain Health Scotland will promote and facilitate entry into the Join Dementia Research database so that (per capita) Scotland has the highest level of research participation in dementia and brain health research anywhere in the world.

Join Dementia Research will feed into the Scottish Brain Health Register – a tool by which additional information not normally held in medical records can be collected. This will enable clinicians to match people to the best research studies for them and generate knowledge to inform clinical practice and public health. This is where health informatics comes in.

Brain Health Scotland oversees the Scottish Dementia Informatics Partnership which was established formally in 2017 and has set the

foundation for the largest and most comprehensive data collection project linked to other existing electronic health records. With individuals' clear consent and operating under the highest levels of data governance, we expect that Scotland will establish itself as the pre-eminent location for brain health knowledge generation, research participation and research investment globally.

our goal is ultimately to assess and improve brain health and therein help prevent dementia.

Through the coordinating activity of Brain Health Scotland we will improve research activity and clinical practice and inform and deliver public health campaigns.

Our singular objective is to improve the brain health of Scotland and therein reduce dramatically the incidence of dementia. ”



The work of Brain Health Scotland

By Anna Borthwick, Executive Lead for Operations, Comms and Public Engagement, Brain Health Scotland

Your brain is who you are. It is your thoughts and feelings, your knowledge and memories. It is curious and creative, and without it you are lost. It controls how you move and every word you say, as well as the friendships you make along the way.

At Brain Health Scotland our mission is simple: to inspire and empower everyone in Scotland to protect their brain health and reduce their risk of diseases including dementia.

We work with all ages, across Scotland, to provide all you need to protect your brain and to join the effort to understand more about this amazing part of who you are.

What we do

Developed in partnership with Alzheimer Scotland, and funded by the Scottish Government, Brain Health Scotland provides:

- expert advice about brain health research, policy and health care
- promotion of positive brain health in collaboration with Public Health Scotland and other partners
- support to ensure health professionals in Brain Health Services can provide personalised prevention plans
- opportunities to join brain health research programmes in Scotland.

Our work falls into two main strands. The first is focused on engaging the public with the concept of brain health. We are developing a suite of partnerships to embed positive brain health behaviours in all walks of life – including in nutrition, fitness, stress management and learning.

One of our first activities is to design educational resources for a variety of audiences, from primary schools through to health care professionals, so everyone can join the effort to better understand brain health and disease.

We are also working with supermarkets and food producers to explore ways of providing clear advice about which foods keep our brains healthy. We will shortly launch a nationwide survey to understand more about how people in Scotland think about their brain health.

Our other main strand of work will be to collaborate with health care partners, including the NHS and pharmaceutical industry. We are actively developing Scotland's first brain health clinics, at which patients will be able to access the information and interventions they need to protect their brain, as well as the Scottish Brain Health Register – a national register of people keen to join research programmes and trials of new treatments.

These Brain Health Services will help to detect and manage the most common brain health problem we face – for example Alzheimer's disease. Through all our activities we expect that, in future, fewer people in Scotland will develop Alzheimer's disease. However, for those who do, we will work to ensure they can access the best assessments, treatments and care of anywhere in the world.



Keeping your brain healthy

We now understand a great deal more about what impacts our brain health than we did even ten years ago. For example, it is widely known that the diseases that lead to dementia start in midlife. The onset of these diseases is driven by many factors – some of which we can't change, such as family history and genetics, but many of which we can, such as lifestyle.

If we eat, exercise and sleep well, we keep our brains healthy. Clean, unpolluted air is important too, so that our brains have a good supply of oxygen. Nothing stimulates the brain more than being with people we care about, having fun and being as calm as we can be at home and work.

Brain Health Scotland is working to ensure this growing evidence base is applied in health care and public health campaigns.

Meet the team

I joined as Executive Lead of Brain Health Scotland in July. Having begun my professional life as a journalist with the Sunday Times and the Scotsman, I have spent most of my career working to engage the public and media with medical research and expertise at the University of Edinburgh. I led communications and fundraising at the Centre for Dementia Prevention, where I had the opportunity to join the European Prevention of Alzheimer's Dementia (EPAD) consortium – a Europe-wide research programme aimed at understanding more about Alzheimer's Dementia and what we can do to prevent and treat it. This began a passion for engaging the public with how we can protect brain health and prevent dementia, which has led me to this fascinating new role with Brain Health Scotland.



I am fortunate to be joined in the team by our Director, Professor Craig Ritchie, of the University of Edinburgh, and Neil Fullerton, our Project and Communications Lead.

Professor Ritchie is a world-leading authority on brain health and has been a senior investigator on more than 30 drug trials of both disease-modifying and symptomatic agents for dementia. He is the Chair of the Scottish Dementia Research Consortium, Professor of the Psychiatry of Ageing and Director of the Centre for Dementia Prevention at the University of Edinburgh.

Neil Fullerton completes our team and joins us as the Project and Communications Lead. Neil has a wealth of experience in managing clinical research studies and supporting research participants at the University of Edinburgh, as well as leading national public engagement campaigns focused on dementia prevention.

What you can do

There are many ways you can get involved with Brain Health Scotland.



Join research – Taking part in brain health research is one of the greatest ways to impact future success: <https://www.joindementiaresearch.nihr.ac.uk/>



Learn about brain health – We will shortly be launching a free online learning course, or MOOC – Massive Open Online Course – about Understanding Brain Health. If you are keen to learn more, please contact the Brain Health Scotland team by email: brainhealth@alzscot.org



Partner with us – We are keen to work with partners from all walks of life, so if you would like to develop a partnership with us, get in touch and we will identify how to embed positive brain health in your area of interest.

The transformation of our digital innovations

By Gillian Fyfe, Head of Digital, Alzheimer Scotland

Alzheimer Scotland has always had one eye on innovation. You'll probably be familiar with some of those things now considered part of our everyday bread and butter provision. Things like the development of models of Post Diagnostic Support, exceptional policy work shaping Dementia Strategies, campaigns like Fair Dementia Care, and services like our 24 hour Freephone Dementia Helpline which provides a vital lifeline to families. You might not yet be so familiar with the work of our Digital Leadership Team, but that's about to change!

For around 10 years, one of our projects, called Dementia Circle, has been finding, sharing and testing products which help people live well with dementia. It started off looking at things like storage containers and door handles which addressed the things that people were finding a bit more difficult day to day. Naturally, as the digital world opened up, and we entered the age of voice assistants and "smart homes", we wanted to make sure that not only were people with dementia able to access these things, but were also shaping their future design and function. With this in mind we developed a Technology Charter setting out the rights and principles that should be expected by families in getting access to technology. Partners from health, social care and industry signed up to support it and committed to listening to people's lived experience. Our next focus was to develop our first app; Purple Alert. Over 10,000 people have signed up to support our community, which becomes your eyes and ears on the ground if someone you care about goes missing. Working with families, emergency services, colleges and other groups we created something unique. When someone who has dementia goes missing, if they aren't carrying a GPS device with them, it can be difficult to locate them and an upsetting experience for their family and friends. It's always evolving, and we will soon be releasing a completely new version with features our community has told us will be useful. You can read more about this on page 31.

On our journey we found that families and people supporting them weren't always sure about what could work, and how to build digital technology into conversations about planning for the future along with other types of Support. We decided to embark on a mission to share the potential, travelling all over the country and delivering learning sessions



to over 2000 practitioners, carers and people living with dementia. We also spoke at conferences in Barcelona, London, Cardiff, Chicago and Berlin, where the international community were keen to hear what we were doing. Scotland is considered to be leading the way in a lot of this work.

We learned a lot from the conversations we had during those sessions, but the overwhelming message was that families and practitioners just didn't know where to start, and really wanted something they could trust which would point them in the right direction. They all had lots of other things going on in their lives, didn't have time to keep up with what the latest developments were, and worried about making the wrong choices. We knew we could do something about that, and with support from the Scottish Government Technology Enabled Care Programme we embarked on the journey to create something to help. We call it ADAM: About Digital and Me, and our vision is that it will be your trusted friend, offering you a bit of guidance when you need it. You can read more about ADAM overleaf.

While developing ADAM, we found ourselves in the midst of a pandemic, and as coronavirus hit, and our Resource Centres and offices closed, we had to adapt overnight to a new style of working. The Digital Team supported our staff in localities to get used to

working from home, redesigning the way they offered services and using new tools to keep in touch with people while we weren't able to see them. It was a steep learning curve for everyone involved, and the virus will have long lasting implications for many families, but what it did show is that technology like video calls and voice assistants can provide a lifeline, and is much more acceptable to our community than many people might have thought. We've seen choirs, baking lessons, garden tours, quizzes and more taking place over the airwaves!

As we look to the future, and whatever that may hold, we continue to embrace the potential that digital technologies can bring. We know that even when our Resource Centres open again, there are people who couldn't access their support due to location, mobility and a whole host of other reasons. Sometimes stepping through the door of a building is just a bit too much, and that brings us to our next innovation; A Virtual Resource Centre. The Virtual Resource Centre (VRC) will offer support to families and practitioners 24 hours a day, 7 days a week. When you step inside the digital door of the centre, you'll be greeted by a host who can speak 25 languages and will guide you through the offering of live and recorded therapeutic activities, a library of information, the latest policy and research

news and much more. You'll be able to find out more about topics like dementia friendly design, find items which could help you day-to-day and even use your phone or tablet to see what they might look like in your home. There will be space to meet with people who have a shared interest, and the chance to be part of a digital community. As ever, we'll be designing this with our community at its heart, giving us guidance and feedback on each aspect, and telling us what will be most useful. We look forward to sharing it with you very soon.

The technology world moves quickly, sometimes scarily so, but these advances in things like 5g, machine learning, artificial intelligence, augmented and virtual reality are what is making our work possible. We'll continue to push the boundaries of what is considered "the norm" and make sure that having dementia doesn't mean that you can't have access to, and benefit, from them.

You don't need to understand how any of these things work to use them – I have no idea about the engine in my car, but I drive it all the same. If it goes wrong, I take it to the mechanic. Digital technology is just the same; what's important is what it can help us achieve, and I firmly believe that we're just scratching the surface.

Introducing ADAM

By Nicola Cooper, Digital Lead, Alzheimer Scotland



Alzheimer Scotland's Digital Team have been leading work funded by the Scottish Government Technology Enabled Care (TEC) Programme, testing if consumer digital products including voice assistants, smart lighting and hot water dispensers can help people living with dementia to stay at home and live well for longer, delaying the need for statutory services like telecare.

Working with families across the country, we found that digital products can be useful, but the biggest difficulties faced were trying to find the right combination of products when you don't know anything about them. To help with this the team created a conversational assessment called ADAM – About Digital and Me – that explores your aspirations and the things that make life good for you, then matches those with a digital bundle tailored to you.

ADAM will only suggest products that have been tried and tested by people living with dementia and by our small expert team, so you can be sure that other people like you have found them useful.

“We don't want to know the future, but we both want to plan for the future as best as we can, to be ready for whatever is ahead. I think this could open up a dialogue about what my husband could be worried about and we could talk it through together.” Kay, whose husband was diagnosed with dementia three years ago.

You can ask ADAM for help with having a good day and catching up with friends, or for something that will reassure your family that you are doing ok. Whatever you would like help with, ADAM will search for the right solutions for you and will make personalised suggestions for technology products that can be bought on the High Street or online.

To make ADAM something which can be available across Scotland we needed to create a digital version of it, and we embarked on a process called CivTech to make that happen. CivTech allows you to pose a challenge and invite companies to work with you to build a solution. With additional funding and support from the TEC programme, we issued a tender and identified Lumera Health, an Edinburgh-based technology start-up company as our partner to do this. The partnership is part of a national technology challenge and we are proud to be the first charity to have been successful in the selection process. At the beginning of March, at the Edinburgh International Conference Centre, we launched ADAM. Having launched ADAM in its core form, we are now working to take it forward as a full product that will be made publicly available and will support people right from the point of diagnosis through their journey with dementia. We hope that thousands of people will find technology to help them live well with dementia with the help of ADAM.

About
Digital
And
Me



Our very own app

By Joyce Gray, Deputy Director of Development, Alzheimer Scotland

We are very excited to present to our community our brand-new Alzheimer Scotland app. For some people we support and their families, you will be already familiar with using apps on your phone or tablet as a way to assist in the organisation of your daily lives. These might be used to organise banking, environmental controls, shopping or help support interests and hobbies.

We want to add to the benefits that apps can bring to you by offering the Alzheimer Scotland app. It will offer our community a range of information sources that will allow instant and easy updates about our current national work. The app also has sections on living well, information for carers and other themes we think will be very useful. Most importantly, it will also offer quick access to what's available in your area.



If you currently access our support, your Dementia Advisor or Community Activities Organiser will be able to update you each week on the groups, activities and information through a direct notification.

The opportunity to develop our own app came during the coronavirus pandemic. A company called PIOTA, who are well known for their health and education apps, offered us the chance to use their existing template and then personalise it with our information and support opportunities.

The app is available on both Apple and Android, just search 'Alzheimer Scotland.' We would love you to download and become familiar with it and, when prompted, accept the notifications so we can easily keep in touch. It would be really beneficial to hear your feedback on the app – so we can evaluate how well it works for you and make changes based on knowing what works best for the people using it.

To download the Alzheimer Scotland app, visit the App Store on Apple and Google Play on Android and search for 'Alzheimer Scotland.'

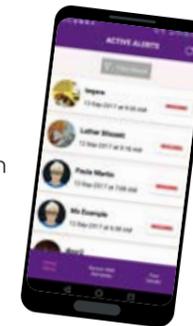
Please
download
the app now
and let's
strengthen our
community!

Purple Alert 2.0

By Tommy Petillo, Purple Alert Coordinator, Alzheimer Scotland

Purple Alert, the first app of its kind in the UK which helps find people with dementia when they are lost, has gone through a major design and functionality upgrade. While the main functionality is still helping to find a person with dementia if they're lost, the new app proposes tailored content to users, depending on where you are in Scotland or when you use the app. Content will be regularly updated, and will provide relevant advice around current events, such as the restrictions that the coronavirus pandemic has brought.

While we were redeveloping the app we realised the pandemic was putting an extra strain on family lives; such as disrupting routines, changing behaviours and increasing distress. We therefore designed some additional features that allow people to continue with their routines and schedules, whilst helping people to remain safe when they're outdoors.



We also focused on improving our services for families before, during and after someone might get lost.

- We designed three toolkits (available on our website) which offer simple step by step advice for families and the Purple Alert community. The toolkits are divided into Preventative, Emergency and Reflective sections, to advise before, during and after a missing occurrence
- In partnership with Police Scotland we developed a new service called 'Return Discussions', carried out by Alzheimer Scotland's Dementia Advisors when a person returns home after getting lost. The new app facilitates organising these discussions with the tap of a button, connecting families, Alzheimer Scotland and the Police to share crucial information soon after a missing person returns home. This information will be securely kept in the Police database and only used by them should the person get lost again.

Due to the upgrades taking place, current users of Purple Alert will need to re-download the app. You can do this via the App Store or Google Play. Please download Purple Alert now and help with our vision of a dementia friendly Scotland.

If you would like to find out more about our digital innovations, please contact Gillian Fyfe by email: gfyfe@alzscot.org or by phone: 07876 790864.

Celebrating



years of

Alzheimer Scotland

We can only provide the support that we offer because of the generosity our supporters show us. Please help us continue to make sure nobody faces dementia alone for another 40 years.

If you can donate, thank you. Here's how you can do so:

Email: fundraisingmailbox@alzscot.org

Website: www.alzscot.org/donate

Call: 0131 243 1453

Making sure nobody faces dementia alone.



Dementia Friends goes digital

By Nicola Kennedy, Dementia Advisor, Alzheimer Scotland

In June this year, Kirsten Oswald MSP submitted an early day motion in Westminster in recognition of Dementia Awareness Week 2020 and the ongoing work of Alzheimer Scotland. The motion was picked up on our local East Renfrewshire Facebook page and, following our acknowledgement and thanks, Kirsten got in touch with us.

She mentioned that the previous Dementia Advisor had delivered a face-to-face Dementia Friends session but that she now had a whole new staff team and wondered whether, under the current restrictions, we could do something online. We then went on to have a 50 min session with Kirsten and her team through the GoToMeeting platform and although it wasn't as interactive as it would usually be face-to-face, it was a great way to highlight some of the ways they can make life easier for their constituents living with dementia and to talk about our work locally.

Almost at the same time, our fundraising team submitted an application to a local funding stream that was set up to respond to the challenges of coronavirus. We felt we could have an important role in delivering Dementia Friends sessions to the many new volunteers that had rallied round in response to the lockdown as they would inevitably be meeting people living with dementia, their families and carers. Fortunately, we were successful and as a result have received some additional funds to carry on delivering these locally to everyone in East Renfrewshire.

Kirsten Oswald MSP:

"My staff and I were pleased to show our support for Dementia Friends by taking part in this and would encourage people in East Renfrewshire to do the same."

"With a growing number of people living with dementia, it is more important than ever that we gain an understanding of the condition."

"The Dementia Friends programme is really useful in giving people an insight into things we can all do that can make a difference to people living with dementia."

We believe this was the first external digital Dementia Friends session that took place and it was a great starting point to consider how we roll these sessions out more regularly. We know that it may be a while before we're able to offer face-to-face sessions, but there's still a demand from people and businesses who want to become Dementia Friends. A group of Alzheimer Scotland staff are now in the process of refining what the session looks like digitally and creating a toolkit for the sessions. Even when we're able to offer our face-to-face support, we will still be looking to maintain our digital offerings and Dementia Friends will be included in this.

Anybody can become a Scottish Dementia Friend.

It's just about understanding a bit more about dementia and the small things you can do to help people living with dementia.



If you'd like to find out more about a digital Dementia Friends session, get in touch with your local Dementia Advisor. You can find out their details by visiting www.alzscot.org/findsupport, by emailing info@alzscot.org or by calling our 24 hour Freephone Dementia Helpline: 0808 808 3000.

Closer to a better future

By Sa Craig, Head of Stakeholder Engagement, Alzheimer Scotland

Legacy fundraising is a significant part of Alzheimer Scotland's income, with just under £2.6 million being given via Gifts in Wills in 2018/19 – all contributing to making sure nobody faces dementia alone. Over the coming years, we are hoping to grow this even further and have recently worked on new materials, which are now available in local Dementia Resource Centres and on our website, to detail how you can support us by leaving a legacy. If you're thinking about including a Gift in your Will to Alzheimer Scotland, we are sincerely grateful for your belief in our work. A legacy is a true reflection of your life, your values and your experiences. Rest assured we never forget this fact and we are proud of every single gift we receive. Here are some of the most frequently asked questions about leaving a Gift in a Will:

Do I really need a Will?

Yes. Everyone should have a Will. If you were to die without a Will, the law decides who is to inherit your estate and the law does not always get it right. It can take much longer and cost more to wind up your estate if you don't have a Will.

I've got a Will already. Can I update it to include Alzheimer Scotland?

Yes. You can add a codicil for any minor changes to your Will, including the addition of a charity close to your heart. When you speak to your solicitor they will advise you if a codicil is the best option.

Will my Gift stay in Scotland?

Yes. All gifts received by Alzheimer Scotland bring us closer to making sure nobody in Scotland faces dementia alone.

Do I need to take anything when I meet with my solicitor?

Yes. All you need is our name, national office address and our charity number and your solicitor will do the rest.

Alzheimer Scotland –
Action on Dementia
160 Dundee Street
Edinburgh
EH11 1DQ
Scottish Charity Number: SC022315

Do only large legacies make a real difference?

No. Each and every gift can make a positive difference to the lives of people living with dementia and their families. While a few of the legacies we receive each year are large ones, the majority are not, and every single gift brings us that one step closer to making sure nobody in Scotland faces dementia alone.



Imagine that one day a simple treatment might exist. Future generations will thank you for your belief in the research carried out now. Our vision is that one day, all forms of dementia will be treatable and eventually preventable.



Demand for our 24 hour Freephone Dementia Helpline (0808 808 3000) will continue to rise. Since 1989, we've supported thousands of people, day and night. Our growing number of local offices and Dementia Resource Centres will continue to offer a warm welcome.



As more and more families need us, we will continue to promote and support the active voice of people with lived experience of dementia. As well as influencing Scotland's dementia policy, we will also continue to influence and improve practice.



To help people with dementia and their families spend more quality time together, or assist with respite, our local community groups and activities will continue to grow across Scotland.

If you don't have a Will at present or wish to update your existing arrangements, you can appoint any solicitor you like. However, we are often supported by solicitors who offer this service for free in return for a donation to Alzheimer Scotland. For more information or to request a legacy pack, contact our legacy team where confidentiality is assured.

Email us: legacies@alzscot.org

Call us: 0131 243 1453



www.alzscot.org/legacy

Virtually anything is possible

By Sarah Cheung, Stakeholder Engagement, Alzheimer Scotland

Every single year, I am blown away with the amount of people who sign up to take part in an event to raise money for Alzheimer Scotland. Whether it's the London Marathon, a zipslide, Kiltwalk, Great Scottish Run, Tough Mudder or something else, thousands of #TeamAlzScot dedicate their time to training hard and encouraging friends, family and colleagues to help reach their sponsorship target.

It's through challenges like these that Alzheimer Scotland is able to provide support across Scotland so, with the coronavirus pandemic cancelling the majority of large-scale events, we launched a virtual events series – Do it for Dementia. Since the launch in April, over 300 participants have taken part in some form of 'virtual' event, raising a staggering £94,000 to date. We've had people like Lindsay Shanley who cycled 250 miles, Euan McLaughlan who ran 50km in his own back garden, Kirsty Lambert and her cardiac class who successfully completed 7 marathons in 7

days and Jeff Hooper who replaced the Edinburgh Marathon Festival with an Elliptical Marathon. Each person has had their own reason for supporting the charity and we're so thankful for their support.

As always, we've also had participation from committed Alzheimer Scotland staff members across the country. From running challenges to walking, cycling, home fitness and personal challenges, our wonderful staff have been getting creative to fundraise for people living with dementia and their carers in Scotland.

There is no doubt that the coronavirus pandemic has impacted substantially on our fundraised income and will continue to do so for as long as events are cancelled. It means a great deal to us that our supporters have continued to raise money during these challenging times; we're very grateful.



Age is but a number

The age range of people who take part in fundraising activities for Alzheimer Scotland is always extremely varied. Toddlers & teenagers and grannies & grandads have all walked, cycled, toddled and ran to raise vital funds. Here is just a snippet from two inspirational people who completed a fundraising event as part of our virtual events series.

Patti proves virtually anything is possible

Patti Davis, from Invergordon, took part in Do it for Dementia, raising funds for Alzheimer Scotland and Age UK by setting herself the task of walking a circuit of her care home every day. Patti entered Mull Hall Residential Care Home in Invergordon at a time when restrictions and lockdown were put in place. Being a social person, this has been difficult for Patti at times but her family have said **"Patti has never been one to shirk away from helping others in the most practical of ways."**

Although Patti lives with dementia, she still vividly remembers the war years and how her country had to pull together. Formally a District Councillor, a foster carer for 19 children and having raised her own 7 children, her daughter Ann Laing said "give a busy person a job and it will be done", a saying that rings all too true for Patti.

Not only did Patti take on this challenge, but she kept everyone's spirits up by singing along the way whilst she did so. Her motto is 'Help us, to help them, to help us' and we are very grateful for that help!



If you would like to find out more about Do it for Dementia, visit www.alzscot.org/doitfordementia. Alternatively, call our Stakeholder Engagement team on 0131 243 1453.

Young fundraiser gets on his bike to Do it for Dementia

Young Jamie Rooney has taken on the remarkable challenge of cycling 100 miles in support of his Granda, as part of Do it for Dementia. Jamie's Granda was diagnosed with dementia a couple of years ago so he decided to raise money for Alzheimer Scotland in his honour.

Jamie said: "My Granda was always up for a laugh and carry on, and his stories were the best. He got diagnosed with dementia a couple of years ago because he was getting forgetful and we had to keep telling him the same thing but he still had his great sense of humour. In the past year he got slightly worse but in the last 14-15 weeks he has got really bad. My Granda doesn't really understand anything now, when you speak to him he doesn't really know what you are talking about and who you are but it doesn't matter as long as we try to spend time with him. A few weeks ago me & my mum stayed with him overnight he never said much but it was good just being with him watching old boxing matches eating domino's pizza at midnight. Last week we took him a walk we had to get him a wheelchair because he can't walk far now but it was good. I want to do the cycle for my Granda and to raise money to help everybody living with dementia. It's horrible."

Jamie's initial fundraising target was £50 and he exceeded that massively by raising £625. Thank you Jamie, we're very proud!



Putting the fun into fundraising



Covering the length of Scotland

During Dementia Awareness Week this year the Link Workers across Scotland arranged a sponsored walk to represent the fact that Alzheimer Scotland were still supporting people with dementia throughout Scotland during the coronavirus. Scotland is the only country with a guaranteed minimum 1 year Post Diagnostic Support service for people diagnosed with Dementia. Link Workers are funded through Health & Social Care Partnerships to provide this unique service in many localities. The distance covered equated to the distance from the Scottish Borders to John 'o' Groats and represented the fact that the Link Worker service is available the length and breadth of Scotland. The Edinburgh team arranged a relay, where they all walked six miles and arranged a socially distanced meeting with one other walker. Some of the famous landmarks covered included Edinburgh Castle, Holyrood Park and the Royal Observatory. The team raised an incredible £5,270 and, on top of that, helped to spread awareness of dementia and the work of Alzheimer Scotland. Well done!

The Corona Bears

The Corona Bears in Largs raised a whopping £1300 for Alzheimer Scotland during lockdown and, in turn, kept the local community smiling during difficult times. Every day during the pandemic, the bears would be 'out and about' and, since the beginning of lockdown, the bears have been involved in many activities from getting married, going on honeymoon and having a baby to partying in Ibiza and camping. The Bears' activities and support have gone global through their very own Facebook page and resulted in their owner creating 500 copies of a calendar capturing all their activities over the past few months which is now sold out.



Inspirational Irene

89 year old Irene Mackenzie, from Haddington, made the most of the coronavirus lockdown by knitting a selection of twiddle muffs for people with dementia,



which are being donated to Alzheimer Scotland. As well as this, Irene has raised an incredible £1390 and counting for our charity, after being motivated by Captain Tom Moore's recent fundraising efforts for the NHS.

The keen knitter started work on the colourful twiddle muffs, which are designed to provide a stimulation activity for restless hands for people with dementia, six months ago and has set a target of creating 100 brightly coloured muffs. Irene said:

"Like so many elderly and vulnerable people, I've found the recent Coronavirus lockdown situation difficult to adjust to in numerous ways. Luckily for me, whilst nowadays I'm a bit unsteady on my feet, I'm still very keen and pretty capable of doing all sorts of crafts and so have been filling the many hours, days and weeks of social isolation by knitting twiddle muffs.

A twiddle muff provides a wonderful source of visual, tactile and sensory stimulation, and keeps hands snug and warm at the same time. I've found there are also benefits for me too – not only is knitting keeping me physically and mentally occupied, it's also making a great dent in my enormous stock of gorgeous textured and coloured wool that I've been buying and hoarding for years ... one of my guilty pleasures!"

A successful partnership

Claire Du Preez, Stakeholder Engagement, Alzheimer Scotland



We are delighted to have been selected as the chosen charity for Scottish legal firm, Brodies LLP.

The launch of our two year partnership comes at a hugely challenging time when we have had to adapt how we work to ensure we are still able to reach the vulnerable people who need us. More than ever it is essential that people with dementia and their families feel connected, informed and part of our community, so we are delighted to have the chance to work alongside this fantastic business to help raise much needed support for our cause.

Alongside planned fundraising challenges and volunteering activity, our partnership with Brodies LLP will aim to raise awareness of dementia, giving their colleagues a better understanding and advice on how to meet the needs of those people who are living with the condition in their community.

With all fundraising events cancelled, face-to-face interaction impossible and our community in crisis, lockdown has been a difficult time to launch a new corporate partnership! However, we felt it was important to continue with our campaign and deliver on commitments where possible, taking time to revise plans so that fundraising, awareness-raising and volunteering efforts could be done virtually and remotely.

Brodies LLP took on the challenge of 'thinking outside the box' by creating a partnership launch video featuring contributions from their own colleagues whose families have been impacted by dementia. The firm's colleagues also organised a virtual pub quiz and coordinated a bespoke Memory Miles fundraiser, clocking up almost 6,800 miles over a week-long period!

Through this variety of fun activity, they have so far raised more than £11,000 for Alzheimer Scotland. We are already looking ahead to further activities to engage the firm's colleagues and clients in supporting our work over the autumn and beyond, until face-to-face events and office fundraising can safely resume. This includes Digital Dementia Friends training, Companion Call volunteering and promoting our new Brain Health Scotland programme in Brodies' popular 'Enlightened Thinking' webinar series.

Nick Scott, Managing Partner at Brodies said: "The impact of Alzheimer's and dementia is profoundly felt by our colleagues, clients and the communities in which we live and work. By working together, we can help raise awareness of the illness, support Alzheimer Scotland in the valuable work it does, and raise money for a cause that is close to many of our colleagues' hearts."

Only through the continued support from our donors and partners like Brodies LLP can we work together to make a positive difference to the lives of people living with dementia and their carers during coronavirus restrictions and beyond. Many of the people we support are already at crisis point and are relying on Alzheimer Scotland as a lifeline to help them through this uncertain time.



Memory Miles

Let's work together! Your organisation could also play a key role in helping us make sure that we can continue to provide vital support for people living with dementia and their families. Get in touch today corporatepartnerships@alzscot.org



40 years of Alzheimer Scotland

Making sure nobody faces dementia alone.



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