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 undertaken 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.

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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.

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 250,000 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/.

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. Throughout 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.

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.

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.

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 not only demonstrated the support for those living with dementia and their families, as well as generating awareness of the disease and 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 are sure we will turn Dementia Awareness Week 2021 into the biggest, most innovative and collaborative week yet.

“We’re still here, still care, and still doing all we can to make sure nobody faces dementia alone.”
The impact of a global pandemic

By Mari 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, their 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 came 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. Vitaly 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 there is also no doubt that we have learnt much from the pandemic and that we are well placed to support people in the future.

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
- Eating well
- Staying connected
- Physical activity at home
- Coping with stress
- Covid-19: Coping with lockdown measures - What might help?
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. 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 & 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 their minds to creating the 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 in 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 was 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 brightened 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 2018 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 2012. 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 brings 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

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: 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 a final 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’ 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.

"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."

"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."
Helpline Reflections
By Jennifer Hall, Helpline Manager, Alzheimer Scotland

When the coronavirus pandemic hit, I had many questions in my head about what would this mean for the people of Scotland? Crucially, what would this mean for over 900,000 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 quickly, and we played a key role in translating what it meant specifically for our dementia community.

Our Freephone Dementia Helpline is here for you 24 hours a day, 7 days a week. If you or anyone you know need information or emotional support call 0808 808 3000.

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 Friday – 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 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 cafe. 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 far 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.

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...
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 him change as he walked through the door. He is no longer a man who visits. His conversation has become more distant. He often talks about birds. It’s as though his already fragile mind has gone into power saving mode. Taking what it needs from its surroundings to survive and no more.

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, not asking 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 intrigued him, becoming increasingly afraid of re-entering it.

It’s a Friday morning and Jane gets ready for her café date as she always does. A little splash 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.

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.}

Dementia in Scotland Issue 101 - Autumn 2020
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. 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 interact 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! 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 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.

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.
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 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.

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

Making sure nobody faces dementia alone.

I am also very conscious of the importance of 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 anniversary. 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 admittance 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.
Since 1980 Alzheimer Scotland, and the previous iterations of the charity, have been-national work which led to the amalgamation. The merger of two organisations, the Scottish Dementia Working Group (SDWG) and Scottish Action on Dementia, was announced in June 1993. The new organisation was called Alzheimer Scotland. The merger was significant because it brought together two organisations that were already working closely on dementia issues. SDWG was the first group in the UK to bring together people with dementia, their families, and professionals to work together on dementia issues. Scottish Action on Dementia was a campaigning organisation that worked to raise awareness of dementia and to influence policy and practice. The merger of the two organisations allowed for a more comprehensive approach to dementia work, with a broader range of expertise and resources available to address the needs of people with dementia and their families. The new organisation was committed to the development of high-quality, co-ordinated and collaborative research.
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.
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.

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 7605 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/fairdementicare 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 01224 455143.
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 an £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 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.

Find out more about Brain Health Scotland overleaf
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 problems we face – for example Alzheimer’s disease. Through all these 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 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.

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 Online Open 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 these 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. Our community, which becomes your eyes and ears on the ground if someone you care about goes missing. Our community, which becomes your eyes and ears on the ground if someone you care about goes missing.

When someone who has dementia goes missing, if you don’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; 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.

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...
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 work in this. 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 expertise free of charge. We were able 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’.

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 let’s strengthen our community!

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.

Introducing ADAM

By Nicola Cooper, Digital Lead, Alzheimer Scotland

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.

Purple Alert 2.0

By Tommy Pettila, 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.
Celebrating 40 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.

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.

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.”

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.
Closerto 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 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 one step 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

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 legacy@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 by 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 zip slide, 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 were 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,’ helping others in the most practical of ways.

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 £1,270 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 £1,300 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 honeymoons 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, raised £590 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.
40 years of Alzheimer Scotland

Making sure nobody faces dementia alone.