Dementia in Scotland



Summer 2022 - Issue 104

Summer Edition







DEMENTIA AWARENESS WEEK ^{30 May}



DEMENTIA AWARENESS WEEK ³⁰ May WEEK - 5 June

Show your support for people living with dementia now and in the future

Get involved

Find out more: www.alzscot.org/DAW2022

#DementiaAwareness



@AlzheimerScotland



Alzheimer Scotland - Action on Dementia is a company limited by guarantee, registered in Scotland 149069. Recognised as a charity by the Office of the Scottish Charity Regulator, no. SC022315 160 Dundee Street, Edinburgh, EH11 1DO, 0131 243 1453, www.alzscot.org

Contents

- 4 Local news
- 8 Campaigning for change
- 10 Events
- 12 Our support

- 14 Tea & Blether
 16 Your support
 20 AHP resources
 22 Digital updates
- 24 Scottish Dementia Working Group milestone
- 26 Brain Health

Welcome

Welcome to the summer edition of Dementia in Scotland magazine. As we slowly move out of the pandemic, Alzheimer Scotland continues to focus on all we can do to support people living with dementia and their families and carers. One of the ways we had to navigate the restrictions was to redesign how we deliver day care, and the result of this is a more person centred, therapeutic approach. You can read more about how this is working in Renfrewshire on page 4. A timely diagnosis of dementia and the support which follows that is vitally important, which is why the news that Scottish Government has increased their investment into post diagnostic support was so welcomed. Post diagnostic support enables people to live well with dementia and maintain independence for as long as possible – you can read more about our '5 Pillar Model of Post Diagnostic Support' on page 8-9.

I would like to take this opportunity to congratulate the tremendous hard work and success of the Scottish Dementia Working Group (SDWG), who celebrate 20 years of campaigning for change (page 24-5). The group have been a global inspiration, and we are immensely grateful for all they do to raise awareness, challenge stigma and influence policy. Our Brain Health Scotland team have developed a new online tool to help everyone find personal ways they can take action to protect their brain and keep it healthier for longer (page 26). We now understand significantly more about what impacts our brain health than we did even ten years ago. We know the onset of the diseases which lead to dementia are driven by some factors which we can't change, such as history and genetics, but many of which we can, such as lifestyle. We will be using Dementia Awareness Week (30 May – 5 June) to talk more about our 'prevent, care and cure' theme, as well as running our new Tea & Blether event – a

wonderful opportunity to connect with others and talk about brain health and dementia. Thank you to everyone taking part across Scotland.

Simmon Hann

Henry Simmons, Chief Executive

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



Phone: 0131 243 1453
Email: info@alzscot.org
Website: www.alzscot.org
Twitter: @alzscot
Facebook: AlzheimerScotland
Instagram: Alzscot
LinkedIn: AlzheimerScotland

Published by: Alzheimer Scotland, 160 Dundee Street, Edinburgh, EH11 1DQ Designed by: Sara Johnston, Creative Designer

Subscribe to our mailing list



Keep informed about our work at Alzheimer Scotland and sign up to get regular email updates. www.alzscot.org/news/sign-up-for-enews

Therapeutic day care

by Fiona Kane, Associate Executive Lead for Localities

Alzheimer Scotland locality teams across Scotland take great pride in supporting our organisation's goal to make sure nobody faces dementia alone.

As we restarted our services across Scotland following the pandemic, our local frontline staff have had to overcome many challenges. Not least of which was to reconnect with our Health and Social Care Partners, initiate referrals to our services, and rebuild day care and community supports.

Across our Renfrewshire Services, this commitment and support has been recognised not only by the people we support, but also by the carers and professionals in the locality.

"Just wanted to say thank you for all the support and help you offer. As you know during the pandemic there have been so many people isolated and now that restrictions have been lifted I have found it very helpful that yourself and your team have worked with us to secure placements for people who are in most need. I think the service offered is essential and is very much appreciated."

- Quote from Social Worker.

When we remobilised the service in May 2021 only 3 of the 32 people who attended day care prior to lockdown were able to return. We worked together with local health and social work teams to promote our new 'Therapeutic Day Care Model'. Together with our community and digital activities, Volunteer Befriending Service and our Dementia Advisor services, the team have quickly progressed from supporting 3 people over

2 sessions each week to now supporting 41 people over 10 weekly sessions.

Our person-centred approach has ensured that each person referred to our service is offered a place within a group where they have similar interests to others, and this has enabled the team to introduce theme days where everyone in the group can enjoy specific activities.

For example, our Friday morning group enjoy football reminiscence sessions and our Wednesday morning group all enjoy singing and participate in an online singing group. We have made the most of the opportunities to link up with other day centre groups by joining online quizzes and 'doggy bingo'.

"Renfrewshire HS(P consider Alzheimer Scotland as a much valued and respected partner and their services in Renfrewshire have for many years made such an incredible difference to the lives of people living with dementia and their loved ones. The services provide flexible, individualised caring support of a very high standard." Shaun Docherty, Renfrewshire (ouncil

> Of course, we have also taken opportunities to recognise important events such as Mother's Day, when we provided afternoon tea and most recently Easter where the groups participated in art activities. The feedback we have received from the people who attend, and their families has been so positive:

"We have noticed a big difference in A's mood since she started the day centre. Initially she was reluctant to come but now she asks every day if she is going and really looks forward to being there. I can't thank you enough, I have really benefited from having time to myself knowing that A is enjoying her time here."

- Husband whose wife has younger onset dementia.

Highland Younger Onset online group

By Karen Black, Dementia Advisor, South Highland

"But you don't look like you should have dementia!"

Being diagnosed with dementia under 65 years of age can affect people differently to those who are diagnosed later in life. People may still be working, have young families, or face a lack of understanding from people. A need was identified for a group to support people with younger onset dementia. Along with our NHS colleagues, we decided to set up a Highland-wide online group offering support for people and their families. The group started in June 2021 with each session facilitated by a member of Alzheimer Scotland staff, and a staff member from the NHS Community Mental Health Team.

The initial session was designed to find out the needs and expectations of those attending and we found that it was the people living with dementia that were coming along rather than families, and that they were looking for peer support.

We now have a small group of people who regularly attend each month. Being part of a smaller group has allowed people to form connections with each other and have the opportunity to talk openly about how they are feeling and share any concerns they have. The group members really enjoy talking amongst themselves, sharing stories and asking each other questions. We're there to offer support when it's required, but the group drive these sessions themselves and the feedback has been very positive.

This is what one of our group members had to say:

"The group is very helpful as we have different experiences from someone who is older. It is a great support being able to talk about my concerns or discuss what challenges we might have with

someone our age. A few things I have worried about and go through, make sense when someone else has previously gone through them or is still going through them. It is a very supportive group and really does help you understand what is happening to you and others who are experiencing the same. I always look forward to the group as I know I can get advice and understanding from others. This is a very important group for young people who are diagnosed as our symptoms are not the same as someone who is older. I have found with having the group, it's a relief to hear it's not just me going crazy, but it is normal for these symptoms to appear. The support we can give each other is very beneficial to us and others."

The group has gone so well, and we would love to build on that success by opening it up to more people – this is something that we are currently looking at.

> If you would like to find out more about this group, please email Hayley Lyons (North Highland) at HLyons@alzscot.org, Karen Black (South Highland) at KarenBlack@alzscot.org or Lesley Hellon (West Highland) at LHellon@alzscot.org

Gaelic Conversations

By Lesley Hellon, Dementia Advisor, West Highland



Starting a new job can be daunting, exciting and strange at the best of times, but never more so than when I started as Dementia Advisor for West Highland in March 2020. Beginning my new role from home and online was scary, worrying, and sometimes lonely. Thankfully I had a great team around me, and although I didn't know anything about dementia at the start, my knowledge and understanding has grown immensely to date.

Many types of dementia can cause problems with speech and language. As the condition progresses a person may struggle to find the right words, use word substitutes, or have difficulty following a conversation. Those that speak a second language might find this exacerbated in their second language first. A person may replace words with the equivalent in a language more familiar to them. Some people can lose the second language altogether, reverting entirely to their mother tongue. If those around them cannot speak this language, it can lead to the person living with dementia feeling isolated as they have trouble communicating with others. This fact sparked a lightbulb moment for me.

I had moved to the Isle of Skye in 2020 from the Wirral, with no previous connections to the island. Around a third of the population speak Gaelic and so I wondered what support was available for people with dementia in this language. After a bit of research, I discovered the answer was 'none'.

Together with our Community Activity Organiser Diane Smith, and with funding secured from Bòrd na Ghàidhlig*, we set up virtual groups where those attending could converse in Gaelic. These groups were facilitated by local Gaelic speakers from all walks of life, such as musicians and community figures but also children from local schools Bunsgoil Ghàidhlig Phort Rìgh and Bun-sgoil Ghàidhlig Loch Abar. The response from people on hearing their native language was incredible. They moved to the front of their seats and their faces lit up. I was simply blown away.

What started as a monthly meeting has increased to bimonthly as we secured further funding. While we are based in West Highland, the groups take place online and we welcome all people with dementia and carers who are Gaelic speakers, no matter where they live. People from the Gàidhealtachd (Highlands and Islands) may move all over the globe but it is incredible how they inevitably find some relation or connection when attending the online sessions. In a way they are like one big family, and it is a privilege to be able to help them reconnect across the miles to share their language and culture through the groups in a way that would never be possible without the internet. We were delighted to have the project

recognised at Duaisean Gàidhlig na h-Alba (Scottish Gaelic Awards) where we took home the Community Award.

Another project highlight for us was participating in Seachdain na Gàidhlig (World Gaelic Week), which aims to raise the profile of Gaelic and increase the use of and interest in the language, music and culture. We hosted a full programme of events with a Gaelic twist, culminating in 'Tea & Shortbread' at the Cuillin Hills Hotel, Portree where we invited local pupils to perform a variety of Gaelic songs. The event took place after the schools had finished for the day and to see the children come back out by choice to entertain the group was very moving.

The benefits this project is having on people we support is clear, and we look forward to seeing Gaelic Conversations continue to grow. Thanks must go to Margaret Nicolson and Anne Martin, both native Gaelic speakers who lead our sessions – without their support we could not deliver such high standard therapeutic work.

Local news

*Bòrd na Gàidhlig is the principal public body in Scotland responsible for promoting Gaelic development, including providing advice to Scottish Ministers on Gaelic issues.

We are looking for Fundraising Volunteers

Join our exciting team of volunteers at Alzheimer Scotland and gain new skills, meet like-minded people, get involved in your local community... and have fun!

Find out more:

www.alzscot.org/volunteer-with-us

Email: events@alzscot.org





Post Diagnostic Support – key developments

By Jim Pearson, Director of Policy & Practice

Following many years of campaigning by Alzheimer Scotland, the Scottish Government made a commitment in 2013 that every person diagnosed with dementia in Scotland would receive a minimum of one year of support from a trained and named Link Worker, based on Alzheimer Scotland's evidence based '5 Pillar Model of Post Diagnostic Support'*.

This guarantee by the Scottish Government is considered world leading, and to date is the only national post diagnostic guarantee of its kind. Alzheimer Scotland's 5 Pillar Model uses person centred planning to put the person and not the illness at the centre of the support they are offered. Central to this model is the role of 'Post Diagnostic Support Link Workers'. They help people to understand their illness, build resilience and develop their individual abilities and strengths, therefore enabling them to live well with dementia and maintain independence for as long as possible.

Receiving a timely diagnosis of dementia is hugely important for people. It provides access to critical help and resources that can enable them and their families to understand and make sense of the changes that are happening, access peer and community support and help plan for the future.

Since 2013 many thousands of people have benefited, however since this national commitment was introduced, fewer than half of those who are entitled to this have been offered it. Alzheimer Scotland has campaigned continuously for the resources required to ensure that every person diagnosed with dementia is offered this.



5 Pillar Model of Post Diagnostic Support

*Alzheimer Scotland's 5 Pillar Model of Post Diagnostic Support provides people living with dementia and their families and carers with the tools, connections, resources and plans which allow them to live as well as possible with dementia and to prepare for the future.

The Covid-19 pandemic brought disruption to diagnostic and post diagnostic services and not only exposed existing gaps but has widened them. The pandemic and the disruption it caused meant that many people were unable to get a timely diagnosis and the opportunity to access post diagnostic support. The impact of that disruption is still being felt by many thousands of people who have not been able to get the help they need, and many have experienced a decline in their physical and mental health. Alzheimer Scotland continued to deliver vital help during the pandemic through 'virtual' post diagnostic support - online or by telephone. While this worked well and will continue to be valuable as part of a blended model, it also means that opportunities for peer support and maintaining community connections have been diminished.

Throughout the pandemic, Alzheimer Scotland has highlighted the growing backlog of people awaiting a diagnosis and post diagnostic support. We have campaigned to ensure that sufficient funding is in place to ensure post diagnostic support is offered to every person diagnosed with dementia in Scotland. That campaign was successful and in November 2021 the Scottish Government announced £3.5m would be awarded to Scotland's Health and Social (are Partnerships to deliver the post diagnostic support commitment for every person who had a dementia diagnosis. This has now been allocated and Health and Social (are Partnerships have been putting their plans in place to use this additional funding to increase their capacity to offer this to everyone who needs it.

Alzheimer Scotland has welcomed this additional funding as an important step forward and we continue to campaign to build on this commitment and ensure that people with dementia, their families and carers are able to access the highest quality of care, support and treatment.

Are you a creative and motivated individual with the passion and drive to support people with a recent diagnosis of dementia to live well in their community?

We are currently recruiting for Post Diagnostic Support Link Workers across Scotland. Current vacancies can be found on our website here:

www.alzscot.org/careers





10

Dementia Awareness Week 2022

By Marri Welsh, Executive Lead, Communications & Campaigns

Alzheimer Scotland do all we can every day to raise awareness and support people living with dementia, their families and carers. Dementia Awareness Week (DAW) is an important chance for us to shine a spotlight on our work and encourage people to find out more about what we do and how we rely on your support. Dementia Awareness Week 2022 will run from Monday 30 May until Sunday 5 June. This year, our theme is 'Let's **Prevent, Care, Cure** dementia together' and over the week there will be a series of events, including our Tea & Blether campaign which will run throughout DAW. You can read more about that on pages 14 and 15.



Prevent.

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, for most people, 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 our lifestyle. Our team at Brain Health Scotland are working to promote brain health through two key programmes:

Brain Health Engagement:

We promote awareness of the core principles of brain health across all walks of life. We work with partners in education, nutrition and fitness, as well as employers and sports associations to promote positive brain health.

Brain Health Services:

th clinics

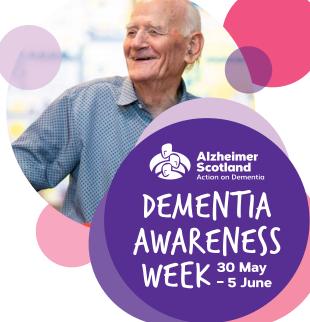
We are developing Scotland's first brain health clinics, at which patients will access the information and interventions they need to protect their brain. We also provide opportunities to join research programmes, so everyone can join the effort to better understand brain health and disease.

Alzheimer Scotland Brain Health & Dementia Resource Centre

ww.alzscot.org

You can follow what's happening throughout Dementia Awareness Week on our website here:

www.alzscot.org/DAW2022



Care.

We have Dementia Resource Centres across Scotland offering friendly, accessible environments for everyone to enjoy. Whether you want to popin for some information, advice or support, our staff and volunteers will be able to help you. Each centre is also a base for our day care services and activities. Our Dementia Resource Centres follow the principles of dementia friendly design and strive to create a local feel, creating a sense of homeliness which we know is important in helping people to feel at ease. Alzheimer Scotland is working towards having a Dementia Resource Centre in every locality within Scotland to ensure we can continue to host innovative support, at the heart of local communities, for many years to come. Our newest centre in Alloa will have its official opening on 1 June.

Our Dementia Advisors and Post Diagnostic Support Link Workers are here to support people with dementia, their partners, families and carers.

You can find out more about our Dementia Advisors and Dementia Resource Centres here: www.alzscot.org/living-with-dementia/gettingsupport Our 24 hour Freephone Dementia Helpline provides information, signposting and emotional support to people living with dementia, their families and carers. Since 1989, our Helpline has supported thousands of people. Staffed by trained volunteers, many of whom have

had personal or professional experience of caring for people with dementia, our Helpline Volunteers can help if you have any questions or concerns, as well as send out free information to carers, family members or people with dementia. Call on 0808 808 3000 or email **helpline@alzscot.org**

Our Action on Rights Team was initially set up during the pandemic to help carers, families and friends of anyone living in Scotland's care homes, supporting meaningful contact and helping navigate care home guidance. The team can also help with access to the range of support that Alzheimer Scotland provide and help you access support provided by other agencies or organisations. Find out more here: www.alzscot.org/action-on-rights

Cure.

The Alzheimer Scotland Dementia Brain Tissue Bank is a collaboration between the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh (ASDRC) and the NHS Research Scotland Neuroprogressive and Dementia Research Network (NDN). The Brain Tissue Bank is able to accept donations of brain tissue from people with a diagnosis of dementia who live on mainland Scotland – helping research both now and in the future. To find out more about brain tissue donation, you can contact our Helpline on 0808 808 3000 or visit **www.alzscotdrc.ed.ac.uk**

The Scottish Dementia Research Consortium (SDRC) is a network of dementia researchers, policy makers and people living with dementia from across Scotland. The SDRC promotes and supports all dementia research in Scotland. They have 5 key research themes – Diagnosis, Fundamental Science, Living with Dementia, Prevention and Informatics. You can find out more about their work here: **www.sdrc.scot**

Join Dementia Research (JDR) is a nationwide online and telephone service that makes it easier for people to register their interest in volunteering for dementia research studies. Anyone can register as a volunteer by visiting the JDR website. You don't need to have a diagnosis of dementia. Signing up is the first step in becoming involved in supporting vital research studies across the nation: **www.joindementiaresearch.nihr.ac.uk**



Alzheimer Scotland Annual Conference **Save the Date** Monday 5 September 2022

#AlzScot22

Events

'Time for You' Carers Fund

By Fiona Corner, Head of Development & Barry Northedge, Carer



Earlier this year, Alzheimer Scotland was awarded funding from the Scottish Government to help support unpaid carers of people with dementia living in Scotland. From this, the 'Time for You' fund was developed. (arers were able to apply for grants of up to £300 to pay for short breaks, gym memberships, hobbies – applications were personalised to people's unique situations. Carer Barry Northedge lives in the Highlands with his wife Margaret who has Alzheimer's Disease. Barry applied to the 'Time for You' fund and used the grant to pay for his fishing hobby. Barry shares his story:

Think like a fish, that's what my wife, Margaret, says about me! What has the Time For You Fund done for me? Dementia doesn't just impact the life of the person diagnosed, it has a profound effect on partners and carers as well, which is where the Time For You fund comes in. Grants support family carers to find a little time for themselves away from caring 'duties'. Time to do something for yourself, a chance to clear your head and recharge your batteries. As a family carer you are 'on call' supporting and looking after your partner 24 hours a day, none of us are likely to resent this, but it is still important to be able to find time to do things for yourself as an individual. Whether that be returning to a hobby, having a short break away on your own, or taking a break away from everyday life

together. I have used my grant to pay for my season ticket to fish on my local River Garry. I can now go and fish whenever there is the chance without having to organise day permits etc. I may still only get away for a few hours each week, but those hours are priceless, time to forget everyday responsibilities (just for a little while) and just stand on the riverbank appreciating the peace and quiet. For a few hours all that matters is where I might catch a fish, where might that fish be 'lying' in the river and how might I tempt it, in essence - 'think like a fish'! That's me - think like a fish. Barry Northedge

'Time For You' (arers Fund

Making sure <u>nobody</u> faces dementia alone.



You, Me & Grief

By Hayley Lyons, Dementia Advisor, North Highland

In 2019 my colleague Sarah and I set out to create a unique support programme for carers bereaved of a loved one with dementia. Carers often lose connections with support services when their loved one dies. We hoped to change this and offer carers a continued structured and informative support system. Grieving the loss of a loved one is one of the most emotional experiences we will have in our lifetime. People often say that grief doesn't go away, but in time you can learn to live with it.

As always, lived experience is at the heart of all we do, therefore we worked closely with bereaved carers to create a 6-week support programme 'You, Me & Grief', providing invaluable insight into the gaps in support and information in their journey which helped us shape this programme. The biggest takeaway from the carers input was that they wanted to meet others in similar situations.

We secured funding to create the 'You, Me & Grief' programme, including topics that were important to bereaved carers such as understanding and coping with grief. Also, practical matters such as benefits and planning a funeral, adapting to change and the importance of looking after yourself. The aim of this programme is to provide information with peer and professional support. We piloted the programme online in spring 2021, with 8 carers from across the Highlands and Aberdeen. The feedback we received was humbling and demonstrated that the peer support element and having all the information in one place was beneficial.

Carers feedback:

"I realised I was not alone in what I was feeling. I felt my input seemed to help others in the same situation as me. Each week I was made welcome by complete strangers which was very nice."

"I feel better able to cope and at least I have an idea of where to go if I'm struggling." "The whole programme has been great and is a must for anyone in this situation."

We then successfully secured additional funding from NHS Highland to create high quality resources that will offer support to bereaved carers all over Scotland. In 2022 we created a resource pack and a leaflet that includes information and signposting to support services.



We have also filmed 'Fiona's Story'. Fiona, a carer from the Highlands, kindly shares her experience, the support she has received from Alzheimer Scotland, and how she is dealing with her grief. It is an insightful and emotional video, and we hope it will support carers in validating their feelings and knowing they are not alone in their grief. Grief can take many forms, and everybody will experience it differently. Alzheimer Scotland is here to offer support and make sure that nobody faces dementia alone.



'You, Me & Grief' will run in different localities across Scotland, either online or in person, offering bereaved carers continued support from Alzheimer Scotland after the loss of a loved one with dementia. Please contact your local Dementia Advisor for information on local courses and resources. For more information on 'You, Me & Grief' or resources please contact Hayley Lyons via email hlyons@alzscot.org or 07554 408479

Tea & Blether

by Sarah Cheung, Stakeholder Engagement Leader

Get ready to blether!



The new campaign - Tea & Blether - follows the format of a coffee morning event with a Scottish twist. This fundraising initiative will be an opportunity for people to host their own coffee mornings to raise funds and awareness for people living with dementia, their families and carers in Scotland.



Coinciding with Dementia Awareness Week, Tea & Blether takes place between Monday 30 May to Sunday 5 June. Already a key date in our organisational calendar, we saw this as a fantastic opportunity to increase fundraising activity and supporter engagement throughout a predominantly awareness raising week.

Participants are invited to sign up for free on our special website, where they can access fundraising resources to help them plan a coffee morning in any setting that suits them. With toolkits designed for getting involved at work, in schools and in the community, this campaign is designed to cater to anyone and everyone with an interest in supporting people living with dementia.

Tea &

Blether

Now you're talking

30th May to 5th June

Fundraising is a core aspect of the campaign, and in addition we aim to compliment this with an awareness raising objective as we continue to reduce stigma around dementia and educate ourselves on the positive impact that social interaction has on our wellbeing and brain. To support this, fundraising toolkits will include flash cards to guide awareness raising during the Tea & Blethers.

Tea & Blether

alzscot.org

ether

lether.alzscot.org

"Alzheimer Scotland is delighted to launch Tea & Blether as a new national fundraising campaign. Some of our local teams across Scotland have been delivering Tea & Blether style coffee mornings for quite a few years and we know our supporters enjoy taking part in this style of event. The successful ingredient is, of course, connection, and we hope that by talking

about dementia, we are able to help raise awareness, reduce stigma and bring communities together to support people with dementia and their carers. Every penny raised for Alzheimer Scotland stays in Scotland and as a charity, we are continually amazed and grateful for our supporters' efforts to ultimately help us ensure nobody faces dementia alone."

Kirsty Stewart, Executive Lead for Stakeholder Engagement.

The campaign joins our calendar of internal fundraising initiatives including our much-loved flagship event, Scotland's Memory Walk, which runs from Friday 16 -Sunday 18 September. For this reason, we took inspiration from Scotland's Memory Walk and used this to create our community focused Tea & Blether fundraiser.

We know our supporters appreciate the flexibility to host fundraising events on a date of their choice and in a location that suits - be that at home, at work or within their local communities and public spaces. Hosting a Tea & Blether in any of these settings is a piece of cake!

We've created an all-in-one fundraising platform for Tea & Blether to make signing up and getting involved straightforward and enjoyable, offering participants access to toolkits and resources at the touch of a button. So, why coffee mornings? We want to give our supporters the opportunity to get involved in fundraising for Alzheimer Scotland which is different to our well-known challenge activities. We also know that Dementia Awareness Week is a time where people are looking for ways to get involved and support our cause.

Through our work with Brain Health Scotland, we also know that social engagement has a positive impact on our wellbeing and brain. Tea & Blether is a chance to enjoy each other's company while supporting our own health and people living with dementia.

Supporters may recognise the name 'Tea & Blether' as Alzheimer Scotland have a history of hosting small scale coffee mornings across our Dementia Resource Centres. This is chance to take the lead and be part of your very own Tea & Blether. We hope to raise £50,000 from this year's Tea & Blether, and with your support we think we can do it.

"They've been absolutely invaluable. We've attended the drop in Cafes which means I can meet other carers and speak to them and see what problems they're having and share mine."

Carer and drop in café attendee.

Every tea poured, cake enjoyed, donation made and conversation shared will support people living with dementia. Wherever you host and whatever your reason, we promise that every penny raised in Scotland stays in Scotland.

You can register now for free and find out more at blether.alzscot.org



Scotland's

MEMORY WALK

Scotland's Memory walk is back for 2022

By Sarah Cheung, Stakeholder Engagement Leader

Our flagship event, Scotland's Memory Walk, is back this September and Alzheimer Scotland is gearing up to welcome and support participants across the country and beyond to walk in honour and in memory of loved ones whilst supporting the work of Alzheimer Scotland.

Registration is free and this year we have added an extra date which means the event will run for 3 days this year – from Friday 16 to Sunday 18 September. This extra date brings flexibility and the option to end the working week by taking part in a social activity with a purpose – something we hope workplaces across the nation will get involved in.

As before, participants are welcome to choose any date in September for their Memory Walk if they are unable to join between 16 & 18 September.

Like recent years, participants are being asked to choose their own route and distance. Past participants have enjoyed choosing a route which holds significant meaning or memories to them. This could be a favourite park from your childhood, the town where a loved one grew up or a favourite stomping ground from your youth. Where could you walk that has a special meaning? Scotland's Memory Walk is not about beating records or conquering hundreds of miles, but we encourage walkers to choose a distance which is a challenge to them. Whether that's 5 miles, 5km or 50km it doesn't matter. Getting out for fresh air and exercise is beneficial for our physical and mental health. Walking can relieve stress, improve our mood, and contribute to keeping our brains healthy. It is also a fantastic way to discover our local areas and the beautiful nature we have on our doorsteps.

Thanks to income fundraised from Scotland's Memory Walk, Alzheimer Scotland can continue to support people with dementia, their families and carers. It has become an important date in the calendar for those who have been affected by dementia through a family member or loved one.

Every penny raised in Scotland, stays in Scotland



Save the date 16-18 September

In 2021, loyal supporters raised almost £132,000 thanks to their dedicated fundraising efforts. Alzheimer Scotland ambitiously hopes to exceed this figure for 2022 so that we can continue to support those who need us.

It's free to take part, so simply sign up to gain access to resources and your ready-made fundraising page. Participants also have access to connect with other walkers through a dedicated Facebook group. Registration opens on Monday 20 June and those who register interest in advance will be contacted by the Memory Walk team with a link to sign up.

Register your interest by visiting memorywalk.alzscot.org

Harry's 90 mile cycle

By Jess Bruce, Communications & Campaigns Officer

Your support

When Harry Racionzer's 90th birthday was approaching, he decided to mark the occasion with a special challenge – to cycle one mile for each of his 90 years!

A retired Angus secondary teacher and former head of Dundee College's science department, Harry often used to cycle and walk around the hills of Angus and Forfar Loch. Now, as he is partially blind, he chose to take on this challenge from a stationary bike in Dundee City Square in April.

Harry is well known around the area for his previous fundraising feats including a treadmill marathon in 2018.

This challenge was inspired by his late wife, Etta, who passed away in September 2021.

Harry has raised nearly £4,000 in total. We would like to say a huge thank you and well done to Harry!

You can support Harry's JustGiving page at www.justgiving.com/ fundraising/90for90forrosetta



Dementia Friends takes off at Glasgow Airport

By Carolyn Irvine, Dementia Advisor, Renfrewshire

A trip to the airport can be a stressful experience for anyone. A confusing, unfamiliar environment filled with people in a hurry to get to their destination. There is a multitude of rules and procedures that must be followed and belongings to keep track of. This experience can easily become overwhelming for someone living with dementia. Preparing airport staff for these challenges can ease the journey and make travel more accessible.

The relationship between Alzheimer Scotland and Glasgow Airport started in July 2019 when I was invited to present at the Passengers with Reduced Mobility (PRM) forum. This group invites representatives from the community, who may have additional needs or challenges when travelling, to come together to inform practice and service in the airport.

Following this, we decided that Dementia Friends sessions would be the most effective way to raise awareness within airport staff and increase their understanding of the simple changes that can make a difference not only within the customer experience they deliver at work, but also in their personal lives. Since the first sessions in December 2019, we have now delivered Dementia Friends sessions to over 70 staff members.

Our focus for the sessions is to provide an understanding of dementia and its impact on people's everyday skills and the communication changes it can bring. It gives staff an understanding of how they can adapt their approach, and how best to understand what lies behind behaviour changes. The sessions, which have been well received, are interactive, with the staff asking lots of questions and sharing their personal experiences with dementia.

Since then, my relationship with the airport's PRM team has developed. They are always interested to hear any feedback I receive about their service, whether positive or negative, or hear about a person's journey through the airport. They are keen to develop the service they are providing wherever they can.

I very much enjoy the work I do at the airport and value the relationships I have built with the service managers there. The time I have spent working to raise awareness in the airport gives me confidence to promote their service and encourage people living with dementia, and their families, to travel through the airport.





Matt Watson, Airport Services Manager said

"Although the entire OCS Team (passenger assistance) are trained to recognise and assist passengers with various needs and disabilities, they all found this extra, more in-depth training hugely beneficial and has been a much welcome addition to their skill set. It has helped bring to life the day-today challenges that meet many of our passengers and we hope this has allowed them to travel with greater ease."

Paul Scott, Terminal Compliance Manager added

"As part of our ongoing work to improve accessibility for all passengers at Glasgow Airport, including those with hidden disabilities, we worked with Carolyn who facilitated several sessions over a period of weeks to allow all frontline departments to attend. Feedback was excellent. It gave us an insight to the difficulties that passengers with dementia would face whilst travelling through the airport and allowed us to make some simple changes to the facilities and how we interact with passengers to hopefully make their journey easier."

Become a Dementia Friend today

Learn a little bit about what it's like to live with dementia and the small things that you can do to help people affected by dementia in your everyday life.

Visit **www.dementiafriendsscotland.org** to watch some short videos to become a Dementia Friend or find out about a Dementia Friends session near you.



Racing Awareness Scotland

By Jonathan Mitchell, Lead for Stakeholder Engagement

Our supporters always go the extra mile, however one group are going even further! Racing Awareness Scotland are a team competing in various motorsport competitions throughout the UK whilst helping causes close to their heart. We are delighted that one of the charities they have chosen to support is Alzheimer Scotland.

Racing Awareness Scotland was founded after team member Alex's late wife Sheila sadly died from dementia. As well as raising awareness, the team hope to direct people to the support offered by the charities involved. Alex himself used Alzheimer Scotland's 24 hour Freephone Dementia Helpline and found it very informative. More importantly though, it was enormously comforting when the role of carer at times became a bit overwhelming.

The team at Racing Awareness Scotland, as well as their partners and sponsors, have raised thousands of pounds for Alzheimer Scotland and pride themselves on being advocates for people living with dementia, their families and carers.



Once again Racing Awareness Scotland are being supported by Pier Brasserie in Edinburgh, who are also fundraising for us. The new racing season

has started, and we wish the team all the luck in the world.



You can keep up to date with Racing Awareness Scotland by visiting www.racingawareness.scot

Online resources from our Allied Health Professionals

By Alison McKean, AHP Post Diagnostic Lead

The Allied Health Professionals (AHPs) are a group of health professionals who support people of all ages to live healthy, active, and independent lives. This can include dietitians, occupational therapists, physiotherapists, podiatrists and speech and language therapists. The AHPs can each make a unique contribution to support people living with dementia to continue to live well and to maintain their connections with families, friends, and communities. This has been more important than ever during the pandemic. The AHPs have been working to provide resources for people living with dementia, their families, and carers. Here are some examples of digital resources that can be used.



(onnecting People, (onnecting Support online

This is an interactive website created by occupational therapists and designers where people can come together to explore ways to live well with dementia. There are lots of different topics with things to chat about, try, play and more!

One topic is 'Physical Activity' as we know there is a close relationship between physical health and emotional and cognitive health. Building in some form of physical activity in our everyday routines can support wellbeing, offering a good source of exercise and a way to channel energy in a positive way. The website encourages people to have a chat about what physical activity means to them. They are then encouraged to try some physical activity and the website offers some examples of how this can be done at home without the need for any exercise equipment. Everyday activities such as gardening, vacuuming, washing, tidying can all be a good source of physical activity.

Another example of a helpful topic on the website is 'Memory Book'. Not only is a memory book useful for planning and setting a routine, but it is also great for helping people living with dementia with talking and conversation. Having a memory book nearby when chatting with family and friends can be a helpful prompt for the



person if they want to talk about what they have been doing. The 'Sharing Memories' and 'Telling your Story' section also contains creative activities to prompt conversation, including finding objects at home that people associate with positive memories or find meaningful and then they can talk about why they have chosen them.

The resources have been tried, tested, and recommended by people living with dementia and those who support them. The website can be accessed at:

www.connectingpeopleconnectingsupport.online

Information sheets and podcasts

A suite of resources has been developed including information on activities at home, physical activity, footcare and diet and hydration. In the 'Physical Activities at Home' podcast there is a discussion about why physical activity is important, including how it can reduce the risks of falls for people living with dementia and how it can alleviate symptoms of stress and anxiety. There are also some great tips on how to keep motivated by planning and setting goals. For example, having a plan to go for a walk after breakfast each day or setting a goal of walking 10 laps of the garden. The podcast discusses how buddying up can also be helpful. Having someone to talk to and set goals with can help keep people motivated with physical activity and helps encourage conversation. The information sheets and podcasts are relevant for people living at home, being supported at home or in a care home setting. The resources can be accessed at:



www.alzscot.org/information-and-resources-by-our-allied-health-professionals

Self-management resources

Occupational therapists have developed self-management resources including an information sheet called 'Practical Tips to help my memory'. Speech and language therapists have created an information sheet about how to make time for conversations

called 'Tips for Talking'. In this information sheet there are tips for people struggling with conversations, but it is also helpful for family, friends, and carers too. The tips include writing down keywords to help keep on topic or bringing an item that





people can point at if they forget a word. It describes how talking is not just about words and that facial expressions and gestures can be helpful too. The resources also include physical exercise instruction sheets and videos that have been developed by physiotherapists. The instruction sheets have information and illustrations on exercises for strength and balance, and strength and flexibility. These are accompanied by helpful videos which demonstrate the exercises in the information sheet. The resources can be accessed at: www.alzscot.org/ahpresources

AHP Dementia webinars

The AHPs have regular webinars sharing their work and practice in Scotland on a wide variety of topics. The webinars are available to join live or you can listen again to the recordings on: www.alzscot.org/ahpwebinars

Social Media

死茶 The AHPs share daily hints and tips and regular updates on their Facebook and Twitter pages. The AHP students on placement also share their work and ideas on the AHP Dementia Instagram page.

Follow them on Twitter @AHPDementia or Facebook AHPDementia



If you would like to know more or would like paper copies of any of the resources, please contact ahpdementia@alzscot.org



ADAM (About Digital And Me) and an update on Virtual Reality

By Rachel McLauchlan, Digital Dementia Advisor

Do you ever feel overwhelmed by technology? Unsure if technology is for you? Have you heard about ADAM? ADAM stands for **About Digital And Me** and is Alzheimer Scotland's online platform that helps you to find the technology you need. ADAM holds an online list of technology products that can be purchased from the high street or from online retailers. You can't buy anything on ADAM,



but you can find out more information about each product including set up time, price, where to purchase, and reviews from real families who have tried out the product before. All the products on ADAM are tested by people living with dementia and their families as part of a project called 'Dementia Circle'.

Dementia Circle supports people living with dementia and their carers to find, test, and share honest feedback on technology products. Our reviewers give their feedback on everything from packaging, how easy it was to set up, and how they have found the product after a couple of weeks of using it. Over the last year, our Dementia Circle reviewers have tested mobile phones, voice assistant products such as Alexa, and smart home technologies.

a you find technolog

Recently our team have been trying out 'virtual reality' as a potential new product for ADAM. Virtual reality headsets allow the user to experience a 3D computer world. They can be on a mountain top, in outer space or watching dinosaurs in a Jurassic landscape. We have previously tried out a virtual reality headset a few years ago with good feedback from our community families. With the release of newer and more updated products, we have been asking for feedback from our Dementia Circle members on how they find the virtual reality experience. Martin, one of our reviewers, has had the Oculus Quest 2 (a type of virtual reality headset) for a week and shares his first impressions below:

"The Oculus is great. The controls take some time to get used to, and you have to download the content. We have a slow connection, so it takes time, but it is well worth it. You really feel you are there – with dinosaurs, riding a rollercoaster, on safari, or in the Space Station to name a few. There is much more to try, and there is a lot of free content especially on Oculus TV. Even just having the headset on sitting in the virtual room is nice!" – Martin

There is so much potential for virtual reality to give new experiences to people living with dementia and their carers. Our team are exploring the new ways we could use a virtual reality headset, including bringing outdoor experiences to people who struggle to leave their home environment or allowing people to virtually travel the world. Once our reviewers have completed their review of the Oculus Quest 2, this product will be available to view on the ADAM catalogue.

All the products have been tried and tested by people living with long-term conditions; focusing on dementia, Parkinson's disease, vision impairment and bearing



To find out more visit www.meetadam.co.uk

Care Visions

The Virtual Resource Centre so far

By Suzie Beresford, ADAM (About Digital And Me) Products and Testing Facilitator

Following the official launch in September 2021, we have continued to develop our Virtual Resource Centre (VRC) with some exciting new features being added. Feedback from people with lived experience of dementia has helped us make our VRC experience more accessible.

A new carer channel is being added which will enable carers to access online support regardless of where they live. This will help them connect to groups for peer support and advice and allow them to share their own stories and experiences.

Moving around the VRC, visitors will see various 'assistive technology' demonstrations. A yellow information icon has been added to highlight the areas that visitors can interact with. Selecting these icons opens an information pop up screen with videos, images and text descriptions. Our partner organisation, Carevisions, has supported the design of a recreational room where visitors can find a range of therapeutic videos and resources. Carevisions will use this

space to share their research and

videos on topics such as sports, physical activities, music and quizzes.

Our digital receptionist 'Fiona's Question and Answer' feature is currently being improved to have commonly asked questions easily accessed.

Our team have been busy collecting lots more content for our Virtual Resource Centre - come on in and have a look. http://vrc.alzscot.org

Digital Health Apps

By Janice McGhie, Digital Lead

If the last 2 years have taught us anything it is the importance of digital support within health and social care. Alzheimer Scotland has a track record of supporting families and practitioners to identify and use consumer technology to improve wellbeing, and we were delighted when we received funding from mPower - a project working with communities to enable people to take the steps needed to live well, safely and independently in their own homes by self-managing their own health and care in the community. Our Innovation and Development Team worked in partnership with ORCHA (the Organisation for the Review of Health and Care Apps) to develop a digital health library website for people living with dementia, their carers and families. At present there are over 360, 000 health and wellbeing apps in the marketplace, and only 20% of apps reviewed by ORCHA meet current standards and regulations. Having access to a collection of safe, accredited health and wellbeing apps can make a real difference to people's lives. Many of the apps have been selected by health and care professionals including Allied Health Professionals, Alzheimer

Scotland staff and our team at Brain Health Scotland. We are also working closely with our Dementia Circle members to further review selected apps.

Knowing that the apps in ORCHA's digital health library have been measured against quality standards and regulations, gives us the confidence to recommend apps to those we support.

We rolled out the library to some of our staff at the end of February 2022. The initial feedback has been incredibly positive, and the next phase of the project is to roll it out to all Alzheimer Scotland staff, partnership organisations and the general public.

> To find out more about ORCHA & Alzheimer Scotland's Digital Health Library visit https://alzscot.orcha.co.uk

The Scottish Dementia Working Group reaches 20 year milestone

By Caroline Russell, Communications & Campaigns Officer

The Scottish Dementia Working Group (SDWG) is a national member-led campaigning and awareness raising group for people living with a diagnosis of dementia in Scotland. The group are funded by Alzheimer Scotland and the Scottish Government and are the independent voice of people with dementia within Alzheimer Scotland.

Over the last 20 years, SDWG members have worked tirelessly to campaign and raise awareness at both national and international levels. They have informed and engaged with Scotland's National Dementia Strategies, and they have worked with health and social care professionals, sharing their lived experiences to help make things better for future generations. The group have travelled across the world to spread their message, challenging stigma, and ensuring the voices of people living with dementia are heard. SDWG is still going strong to this day and is known worldwide. Visitors from countries as far away as Japan have come to Scotland to see how the group is run and when they have returned home, they have formed their own dementia working groups.



As they reach an amazing 20 years of campaigning, we look back at the history of the SDWG.



In 2001, James McKillop, who had been diagnosed with Multi Infarct Dementia, met Social Researcher Heather Williamson. They both wondered why there were no groups for people with dementia.

In 2002, they organised a conference in Dundee for professionals and people with dementia. Attendees included some professionals who went on to become co-opted members of the SDWG. Staff from Alzheimer Scotland and Turning Point also attended with people with dementia, and it was here that the idea for a group was endorsed, and a small steering group was established. The group then wrote a constitution and more members

joined. The Scottish Dementia Working Group (SDWG) was born, with James as its first Chair.



James McKillop

Alzheimer Scotland, with its greater access to people with dementia and their carers throughout Scotland, took over the running of the responsibilities and appointed a staff member to support the group. James stood down as Chair in 2005 and was replaced by Edward McLaughlin. The group's influence continued to grow, with members speaking at a variety of events and responding to consultations from the Scottish Government and the NHS.

By 2009 the group were well established with an active committee and a wider membership. Members attended the Alzheimer's Disease International Conference in Singapore. They met with Scotland's First Minister and were consulted about Scotland's first ever National Dementia Strategy. Agnes Houston became Chair in 2010 and the group continued to go from strength to strength. In 2012, the SDWG celebrated their 10-year anniversary, receiving greetings and well wishes from individuals and organisations around the world. Henry Rankin was also elected Chair in that year.

Increased funding in 2013 from the Scottish Government saw the extension of the SDWG staff team. Members decided to focus on building a stronger group, raising awareness of dementia within the transport sector, and training for GPs. This year, Agnes Houston was awarded a Lifetime Achievement Award at Scotland's Dementia Awards for her campaigning work.

The group continued campaigning, taking their message internationally and presenting at conferences in Copenhagen and Budapest in 2016.

Group members took part in the short film 'Living and Learning with Dementia' to show that people with dementia can continue to learn new things after their diagnosis. Former Chair, Henry Rankin, was recognised for his hard work by receiving the Lifetime Achievement Award at Scotland's Dementia Awards. We would like to thank everyone who has been involved with, and supported the SDWG over the last 20 years, in particular the amazing members who have given their time to the group.

SDWG member Kenny Moffat said:

"I have been mightily impressed by the commitment and enthusiasm of the group – individually and collectively – to identify key priorities and champion the cause of those with lived experience as

well as carers. I see the SDWG as having a key role to play in spreading the word about dementia and hope to continue to contribute in a worthwhile way as time moves on. Being part of the SDWG – albeit online – has been a wonderful life experience for me and one that I cherish."





In 2018, Archie Noone (then Chair) travelled to Chicago for the Alzheimer Disease International Conference where he presented a poster that showcased the 'Living and Learning with Dementia' film.

In March 2020, like everyone else, we went into lockdown. The SDWG had been an active campaigning group who met on an almost weekly basis in person, attended conferences and meetings throughout Scotland as well as national and international events. Overnight that changed. Group members had to adapt to a whole new way of working. As well as trying to cope with the restrictions and stresses that the pandemic caused, members now had to move all their engagement online. Many of our members took to this new way of working straight away, and for members in more remote areas or who found travel difficult, it provided more opportunities for engagement and involvement. The Covid pandemic had a disproportionate impact on people with dementia, their families, and carers. It was more vital than ever for us that the voices of people with lived experience were being heard.

Members began sharing their stories and experiences through a series of Blogs hosted on the Alzheimer Scotland website. This has been hugely popular and formed the basis of a presentation at the 2021 Alzheimer Europe Conference which members were able to attend online.

Founding member of the SDWG James McKillop said

"The SDWG was so successful that it was recognised by the Scottish Government, and at the tenth anniversary, the First Minister hosted a reception at Edinburgh Castle in appreciation. The group has influenced how people with dementia are treated, not just in Scotland. The successes are too numerous to mention. Thanks to the members and Chairs, we can proudly look back and say - we did it our way, we made a difference."

In 2021, we were saddened by the death of Archie Noone. Archie was a former Chair of the group and Vice Convenor of Alzheimer Scotland - his campaigning work had been celebrated earlier in the year when he was awarded the Lifetime Achievement Award. 2022 brought some more sad news when we heard that Henry Rankin, another former Chair, had passed away. Both Henry and Archie were passionate campaigners who had contributed so much throughout the years. Both were well liked, highly respected and will be greatly missed.

As we start to slowly move out the pandemic, we are thinking about the way forward for the group. There have been lots of changes over the last twenty years. We have met many wonderful people, made many friends, and sadly lost some friends along the way. 26

My Brain Health Plan

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

'My Brain Health Plan' is a new interactive online tool which has been designed to help everyone find personal ways they can take action to protect their brain and keep our most valuable organ healthier for longer.

There are lots of different things that can impact the health of our brains and in turn influence our risk of developing the brain diseases that can lead to dementia. Not all these things are within our control. However, there are lots of ways we can all look to make positive changes that can help protect the health of our brain throughout our lives.

With so much information out there and conflicting reports of which habits might be good or bad for our brains, sometimes it can be tricky to know exactly where to begin. It can seem like every other day there is another headline about which lifestyle factors might increase or decrease the risk of developing a brain disease.

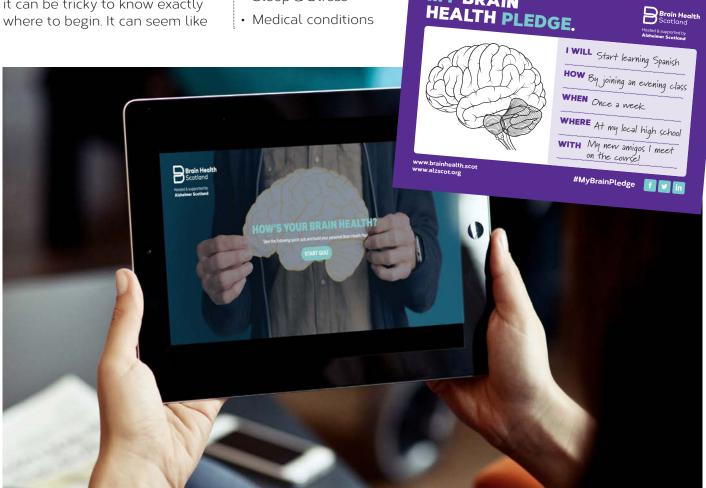
The 'My Brain Health Plan' online quiz aims to cut through all this noise. The quiz guides users through a set of quick questions about their life and routine and uses this information to generate evidence-based advice and top tips that are tailored to them.

The quiz focuses on 6 areas of our daily lives, all key to keeping our brain healthy:

MY BRAIN

- Exercise
- Weight
- Socialising
- Alcohol & Smoking
- Sleep & Stress
- Medical conditions

Once users have received their tailored advice, they are then encouraged to use this information as a starting point to set a range of Brain Health Pledges. These pledges are personal goals that can make it easier to take positive steps for better brain health. Setting small, manageable goals like this can help with staying on track and keeping motivation up over time. Visit the Alzheimer Scotland and Brain Health Scotland social media channels for inspiration then give the quiz a go and build your own personal Brain Health Plan. Take the My Brain Health Plan online quiz here: brainhealth.scot/brainhealthplan



Brain Health



Hosted & supported by Alzheimer Scotland

BUILD YOUR PERSONAL BRAIN HEALTH PLAN AT

brainhealth.scot/brainhealthplan







Worried about dementia?

0808 808 3000

Call our Freephone Dementia Helpline We're here for you 24/7

alzscot.org

When you have finished with this magazine please recycle it.

Alzheimer Scotland - Action on Dementia is a company limited by guarantee, registered in Scotland I49069 Recognised as a charity by the Office of the Scotlank Charity Regulator. no. SC022315 160 Dundee Street. Edinburgh. EH11 1DO. 0131 243 1453. www.alzscot.org