

Dementia in Scotland



Spring 2018 – Issue 95



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Contents



p12

Find out what we're doing to make sure nobody faces dementia alone.



p7

Read about our award-winning partnership with maximum-security prison HMP Shotts.



p22

Find out how you can get involved in one of our Memory Walks.



p17

Scottish international rugby player, Henry Pyrgos talks about becoming a Dementia Friend.



p10

Find out what's not to be missed at this year's Annual Conference.



p25

HSBC's Charlotte Lowry cycled 400km to raise money for Alzheimer Scotland.

DIGITAL
PARTICIPATION
SIGNATORY

Alzheimer Scotland is a proud signatory of the Digital Participation Charter. This means that we are committed to ensuring that people living with dementia and their families have access to digital support and expertise across Scotland.

Welcome!

In the last edition of Dementia in Scotland we looked back at the great successes of 2017 and thanked you all for your help throughout the year, and in this edition, we're looking forward. Although it's only April, we have already made some good progress with this year's plans and there are some very exciting future projects to tell you about. This year's Dementia Awareness Week runs from 4-10 June and we are encouraging people to get involved with activities near them. Take a look at page 8 for more information on what's happening in your area. Alongside Dementia Awareness Week comes our Annual Conference, which will be held at the Edinburgh International Conference Centre on Friday 8 June. Whether you're a regular attendee or have never been before, you should head to page 10 to find out what to expect.

In this edition, we also wanted to give an insight into what we are delivering to support people across Scotland, and how we are using the vital funds from our supporters to achieve this. We truly want to make sure that nobody faces dementia alone and that is why we are using our funds to provide as much access to Dementia Resource Centres, Dementia Advisors, Community Activity Organisers and Volunteer Co-ordinators as possible. Alongside this support are the services we provide, which are commissioned by the local Integrated Joint Board or directly by individuals such as Link Workers and Day Services. When this full range of support is in place, we can ensure that people are not isolated, lonely or disconnected and we can help people to develop the skills and abilities needed to live well with

dementia for a long time. Find out more on page 12.

Sadly, we do not yet have the funds to provide this full range of support in every area, but we are determined to change this. This is why our Community Fundraisers and our Fundraising Team will be working hard this year to increase our support in localities and help us achieve this crucial level of support. We would be most grateful for any assistance you can provide and please get in touch with your local service or with our national office if you can help in any way.

We will also be making sure that the voices of our members, people living with dementia and their families are heard in each locality to ensure that the policy aspirations of the National Dementia Strategy are delivered across Scotland. We are now on our third National Dementia Strategy and our models of post-diagnostic support, integrated care and advanced care have been accepted and are central to these strategies. However, at present too many people are waiting for support and services, and this is not improving quickly enough to deliver the core elements of the strategy. Some areas are making good progress but too many are not, which is why our local teams are working hard to bring people together to make the case that more urgent action must be taken to implement these policies. If you want to help with this, please come along to one of our local engagement sessions and get involved. See page 19 for more details.

You may recognise new Dementia Friend, Henry Pyrgos, as a regular feature in both the Glasgow Warriors and Scottish rugby squads. Henry has

joined us to help celebrate reaching the enormous milestone of 50,000 Dementia Friends in Scotland. If you're a rugby fan, or want to know more about the Dementia Friends Scotland project, see pages 17 and 18.

Although September may seem like a long way away, it's never too early to sign up for our Memory Walk series. This year we have a grand total of 15 walks, which means people all over Scotland will be able to participate. To discover more about our Memory Walk series, and to hear from some familiar faces see page 22.

With so much going on, 2018 is shaping up to be another exciting year for Alzheimer Scotland. As ever, I'd like to thank everyone for their support and I look forward to working with you all in the upcoming year.

Finally, I must share some incredibly sad news. The President of Alzheimer Scotland, Lord Sutherland of Houndwood, has sadly passed away aged 76.

Lord Sutherland was an incredibly accomplished man, championing radical reform in his academic life and driving fundamental changes in care for the elderly. It was his tireless work that led to the Free Personal Care policy being developed.

He will be very much missed by our organisation and by the many other organisations that he supported.



Henry Simmons,
Chief Executive
Alzheimer Scotland

Dementia Friendly Dunblane – the story so far

By **Breda Seaman, Committee Member, Dementia Friendly Dunblane**

Established in January 2017, Dementia Friendly Dunblane brought together key stakeholders, carers and people living with dementia to work towards their goal of opening a Dementia Café in the city. The group had remarkable success, and the café opened its doors on 20 September 2017. This dementia friendly space is open every Wednesday from 2–4pm, at the Braeport Centre and is run and facilitated by 23 volunteers.

The café has become a hub of activity with entertainment provided by local musicians, artists and story tellers. Other activities have included a screen show

of old Dunblane, Stirling and the Forth Valley provided by the Stirling Council archives, and an engaging reminiscing session held by volunteers from the University of Third Age (u3a). Other regular visitors include pupils from St Mary's Episcopal Primary School who bake cakes, and Dunblane High School pupils who play games and provide manicures and massages. These visits provide inter-generational experiences for the people with dementia which are always well received.

Since opening, the café has successfully gained funding to train volunteers; introduced a community 'Playlist for Life' and received funding from the Tesco Bags of Help scheme to improve the sustainability of the café.

The café hopes to continue its partnership with local businesses and increase awareness in the community to make Dunblane a great place for people with dementia, their families and their carers.



More info

For more information about your local area visit our website www.alzscot.org

A Swedish visitor comes to Shetland

By **Pernilla Edström, unit manager from Ekdalagårdens Dementia center in Sweden**

In December, I visited Lerwick, the main town in Shetland, to get a sense of how they do things in Scotland.

I was shadowing Ann Williamson, a Dementia Advisor who works for Alzheimer Scotland. Ann and her colleague Laura work with people with dementia, and their relatives, who live at home. Ann and Laura work to create social activities for people with dementia to help them live at home for longer.

Ann and Laura work together with two Dementia Nurse Consultants, Alan and Stephen, who come to the various activities and are on hand to give medical advice and have conversations with relatives. This means attendees do not need to visit their GPs whenever they have a dementia-related question. Alan and Stephen contact psychiatrists and geriatric nurses in Aberdeen via a video link.

Alan and Stephen, as well as Ann and Laura, are also involved in research in Luleå-RemoAge, in Sweden, which deals with innovative welfare technology such as supervisory cameras.

One of the biggest differences between Sweden and Scotland is that most people with dementia still live at home, within the community. I was also very impressed by the level of support on offer from Alzheimer Scotland and Dementia Nurse Consultants Alan and Stephen.

The efforts of Alzheimer Scotland to ensure people with dementia live in their own homes for longer, and the levels of contact and support available for relatives is something we could introduce where I work in Härryda Municipality. I think the efficient way that Alzheimer Scotland work with doctors by a video link is also something we could adopt.

I am the first Swedish person to become a Dementia Friend, which Alzheimer Scotland provides to people who are interested in raising their



dementia awareness. I have also been interviewed by BBC Shetland Radio, which was an interesting experience!

I will definitely keep in touch with Ann, Laura, Alan and Stephen to exchange ideas, approaches and experiences. They even invited me to the conference, RemoAge, in Luleå in January 2018.

More info

For more information on what's going on at our Shetland Dementia Resource Centre contact the Dementia Advisor, Ann Williamson at awilliamson@alzscot.org

Retired farmers social group

By Jill Rennie, Dementia Friendly Community Worker

A pilot scheme in Castle Douglas is inviting retired farmers, including those with dementia, to get together and have a cuppa.

A dementia diagnosis can have an enormous impact on a person and their family, but if that person is also an active member on a farm, then the business can be affected as well.

We want everyone in Dumfries and Galloway to live in an enabling, supportive community and feel valued and understood. I noticed that when farmers or farm workers retired they could often become isolated and lonely, and they lacked opportunities to meet other farmers socially. I began to wonder if a retired farming social group could be set up, consisting of all

people who have worked in agriculture, including people with dementia.

This led to the launch of the retired farming group, as a pilot initially, in Castle Douglas. I went along armed with all sorts of props to encourage conversation, but I didn't need any of them. Once everyone sat down, off they went, telling stories and reminiscing. It was great to see everyone enjoying themselves chatting and laughing.

Farmers who have sold up and moved out of the farm are totally removed from a life they lived since birth. Where are they now? How are they keeping up with their friends? I think that if we can get these ex-farmers to take the initial leap and get out of the house then this would be a terrific opportunity to get retired farmers, with or without dementia, together.



We would love to see these meetings become a regular event in the calendar of retired agricultural workers, including those who are living with dementia. We are still trying to think of a quirky name for our group though, and I'm open to suggestions!

More info

Do you want to learn more about this group, or have a suggestion for a name? Get in touch with Jill Rennie at JRennie@alzscot.org

Bellahouston Park allotment refurbishment

By Polly Mark, Dementia Advisor

Our allotment at Bellahouston Park is getting a facelift this year, thanks to a £6756.78 sponsorship from HSBC. Families living with dementia will benefit from much needed site improvements including extended paved areas with ramp access; building a large storage shed; adding additional seating and raised beds; and erecting a covered pergola.

A dedicated allotmenteer Willie Caldwell has benefited greatly from this project.

"I look forward to taking Anna to the meets at the allotment every week and can't wait to see the improvements. The allotment means a lot to us – I am interested in gardening and we learn a lot from talking to friends who attend. Meeting others who are in the same

boat as us helps us get through the day, something which can occasionally be quite challenging. We look forward to visiting the allotment in 2018 and hope that we have good weather to reap the benefits of fresh vegetables."

The group has inspired Willie to take up new hobbies such as pyrography (etching images on to wood) and last year he made us a sign for our new shed. The couple go to a Craft Café in Govan run by Impact Arts where Willie has been drawing, painting and learning to use a sewing machine. Not to be outdone, Anna has produced a magnificent oil painting which hangs proudly in their living room and this has even been made into Christmas cards.

As a Dementia Advisor who has been involved in the allotment project going into its seventh year, I am absolutely delighted for the group. So many



people have enjoyed gardening here and now with the improvements more families can continue to benefit from this legacy.

More info

For information about gardening opportunities in your area, please contact your local Dementia Advisor by visiting www.alzscot.org

Pfizer ends research into treatment for Alzheimer's disease

By Nicole Nayar, Information Manager

Pfizer, one of the world's premier biopharmaceutical companies, has made the decision to end its neuroscience discovery programme into Alzheimer's disease and Parkinson's disease, resulting in the loss of around 300 jobs.

Following a comprehensive review of its research efforts, Pfizer has made the decision to relocate the funding to areas where it already has strong scientific leadership.

In a statement to National Public Radio (NPR) a spokesperson for Pfizer said, "Any decision impacting colleagues is difficult; however, we believe this will best position the company to bring meaningful new therapies to market, and will bring the most value for shareholders and patients."

This news will come as an enormous disappointment to people living with Alzheimer's disease all over the world. There are 90,000 people in Scotland living with dementia right now and that number is set to rise. Here at Alzheimer

Scotland we continue to support dementia research, looking not only into treatments and cures, but also into improving the care provided for people living with dementia right now.

More info

For more information on our research involvements go to www.alzscot.org/research

Award-winning partnership with HMP Shotts

By Lorna Hart-Thomson,
Dementia Advisor

In 2016 we were contacted by HMP Shotts, a maximum-security prison in Scotland, and asked to talk to the staff and prisoners about dementia. The number of older people and people with dementia in prisons is growing rapidly and significantly, and this presents challenges in providing appropriate care. Compared with the rest of the population, prisoners have a higher rate of dementia risk factors such as head injury, smoking, drug and alcohol misuse, and low educational attainment. However there has been very little research into dementia in prison. This means that we do not know how many people are living with dementia in prison, and we also know very little about the experience of living with dementia in prison.

The innovative partnership between HMP Shotts and Alzheimer Scotland began as a pilot project, and was the first of its kind in Scotland. We initially engaged with 13 prisoners through a dementia awareness session and 16 staff through a Dementia Friends session. We thought that this approach



would allow us to see if there was a need for dementia awareness in prisons. From the first session it was evident there very much was a need. We met with a man who had been diagnosed before he was convicted who said "Life within prison is far less stressful, outside I was stressed and life was difficult. There were lots of decisions I could not make due to my dementia, and my memory was really poor. In prison I do not have to think. I get told when to get up, when to work and when my meals are. It's easier in here."

Another man whose gran has dementia asked "How do I tell my gran I am in here? She thinks I am 14 and have not returned from school. She can't visit anymore and cries on the phone." This told us that not only did we need

to engage with prisoners but that it was essential to link with families as well.

From these two case studies alone, we felt it was paramount to continue the partnership. We devised an annual work plan for 2016/2017. This would enable us to work with 'hard to reach' groups, allowing dementia awareness to reach all. To date we have engaged with over 300 prisoners, over 60 staff and over 100 family members through one-to-one discussions, group work and attending visits with the Alzheimer Scotland Memory Bus. One staff member said "I know you are here primarily for prisoners, but the staff are ageing too, I'm worried about myself."

We are delighted to have won the Scottish Dementia Award 2017 for Most Innovative Partnership. This project has allowed us to explore dementia friendly environments and what this means for prisons. Due to the success of this work, the Scottish Prison Service are now working with us to provide Dementia Friends to staff in all prisons.

More info

For more information on this project, contact Lorna Hart-Thomson at lhart-thomson@alzscot.org

Dementia Awareness Week 2018

By Beccy Jardine, Campaigns and Social Media Manager

Dementia Awareness Week – making sure nobody faces dementia alone

We are just a few months away from Dementia Awareness Week which this year runs from Monday 4 to Sunday 10 June.

Dementia Awareness Week is our chance to let as many people know about dementia as possible. It's also a great opportunity for us all to change how Scotland talks and responds to dementia.

This year, the key theme of Dementia Awareness Week is making sure nobody faces dementia alone. We want to help people understand that learning just a little bit more about dementia can make a big difference to people living with the disease. It's vital that people living with dementia feel recognised, valued and supported in their local communities.

We also hope to reach more people than ever to make sure people living with dementia have access to the support and information they need within their communities throughout Scotland.

We have big plans up our sleeve for Dementia Awareness Week and we can't wait to share them with you. We would love for you to be a part of Dementia Awareness Week 2018 – we can only make the week a big success with your help. There are lots of ways to get involved:

Order an awareness pack to learn more about dementia

Help us spread the word about dementia by ordering one of our awareness packs. These includes lots of helpful information on dementia, what it is like to live with the disease, along with information on the support and services Alzheimer Scotland provides.

Get involved on social media

Throughout Dementia Awareness Week we will be posting information on dementia and the support we provide across our social media channels. We will also be starting conversations about dementia and asking for your experiences. You can get involved by commenting, liking or sharing our posts. You can also contribute to the conversation by using #DementiaAwareness on your own posts.

Spread the word about dementia through an awareness event

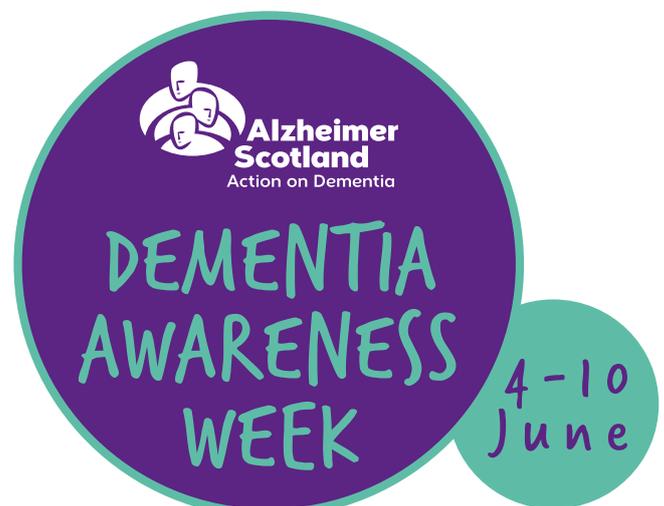
Do you want to hold an event to let your local community know more about dementia and the support Alzheimer Scotland can provide? Get in touch and we can send you everything you need for a successful event.

Support the work of Alzheimer Scotland: donate or hold/attend a fundraiser

Your support means so much to us – with your help we can make sure nobody faces dementia alone. If you want to hold a fundraiser, we can support you from start to finish and give you great ideas for fundraising events, like a Tea and Blether.

"Dementia Awareness Week give's us a chance to be much more visible to the public and let them know who we are and what we do. This raises awareness of the support people can access from us, as well as how to get involved in fundraising, which helps us to sustain the support provided in our localities based in the heart of communities across Scotland."

Marilyn Boyd, Community Fundraiser



A message from Henry Simmons, Chief Executive:

This year, for Dementia Awareness Week, we will be focussing our efforts on making sure nobody faces dementia alone and introducing you our vital work at the heart of local communities. Our network of Dementia Resource Centres, Dementia Advisors, Community Activity Organisers and Volunteer Coordinators are funded by donations across the country. We could not do this work without them. In many areas we have not been able to provide all of these crucial resources. With your help we can change this. We can continue to deliver and to expand these vital forms of support. Be part of Dementia Awareness Week 2018 and help us to make a big difference for everyone living with dementia here in Scotland.

“Why should you take part in Dementia Awareness Week? We all know someone with a diagnosis of dementia, whether it is a relative, friend or neighbour. We want to raise awareness and with your help, people living with dementia will receive the support they need. No matter if you are at school, work or retired we need you to help us make sure nobody faces dementia alone.”

Lorna Hart-Thomson, Dementia Advisor



To sign up to take part in Dementia Awareness Week or donate, visit www.alzscot.org/daw



Alzheimer Scotland Annual Conference

Making sure nobody faces dementia alone
Friday 8 June 2018, EICC, Edinburgh

By Kim Kilgour, Conference and Events Manager

Do you share our passion for improving the lives of people living with dementia and their families? Perhaps you're already helping to make a difference? Either way, please join us at the Alzheimer Scotland Annual Conference where you'll meet bold practitioners and inspirational leaders, and hear the latest big ideas in policy, practice and research.

This year's conference will explore how we can work together to make sure nobody faces dementia alone and the importance of closing the gap between policy aspiration and lived experience. We'll hear the personal stories of people living with dementia, including both those with a diagnosis and family carers. You'll also have the chance to ask pertinent questions of the government as well as a panel of sector experts.

With a stimulating programme that includes contributions from local and national voices, and a choice of six breakout sessions, you'll have the flexibility to tailor the day to suit your specific interests.

Sessions include:

- Research: Care today, cure tomorrow
- Practice: Personalised support
- Citizenship: Be heard!
- Diagnostic support in primary care: Connecting people – connecting support
- Spirituality: Is your soul well fed?
- Digital: Making the difference

You'll take part in our Next Big Innovation live-audience vote and hear from members of both the Scottish Dementia Working Group (SDWG)



£95 early bird members' rate available until 30 April.
 Free tickets available for people with dementia and their carers.
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www.alzscot.org/conference2018



and the National Dementia Carers Action Network (NDCAN) who will be participating in key presentations throughout the day. They will share real stories and provide unique insights on the progress made to date, as well as hosting extended displays within the main exhibition area.

Our dynamic exhibition area will have it all. You'll see everything from product demonstrations and poster-board presentations to show-and-tells and videos. Also, for the first time ever, there will be a dedicated Alzheimer Scotland Creative Practice Showcase, which will promote a wide variety of our

vibrant projects. For a full list of this year's exhibitors please visit the website. If you are interested in exhibiting contact conference@alzscot.org for further details.

The event will bring together a diverse audience of over 500 delegates including people with dementia, carers, policy makers, national and local government staff, academics, health and care professionals, staff from Alzheimer and dementia associations, along with representatives from the pharmaceutical industry, financial, legal, property and technology sectors.

You won't want to miss the most important conference for Scotland's dementia community. It's sure to leave you feeling inspired and give you new connections, creative solutions and new ideas that will help us all to make sure nobody faces dementia alone.



Next Big Innovation

New for 2018, we will hear from the finalists of the 'Next Big Innovation'. This unique partnership opportunity aims to find the next advancement in dementia care, offering supportive funding to help turn innovation into reality.

We are looking for innovative and creative new ideas that offer practical solutions to support people living with dementia, as well as their carers, partners and families. Delegates at our annual conference will hear pitches from the finalists and take part in a live-audience vote to choose the winning innovation.



"It's a fantastic opportunity to network with people, to share new ideas and to listen to different speakers. You get a good idea of what people are doing nationally and internationally in the world of dementia care, and you have the chance to listen to the voices of people living with dementia to hear what their needs are."

Jason Corrigan, Barchester Healthcare



"It's a great opportunity to network with other organisations and to get a bit more understanding of the work that goes on throughout the year."

Gail, Balhousie Care Group

Making sure nobody faces dementia alone.

By Henry Simmons, Chief Executive



Since its formation, Alzheimer Scotland has been determined to do as much as possible to provide direct help and support for people with dementia and their families, and at the same time be a leading force for change at all levels in society.

Our Dementia Helpline, for example, has been available 24 hours a day, seven days a week, 365 days a year for 29 years now. Many people have used this vital support and, over the past ten years, we have been gradually using our fundraised income and donations to build on this to create strong platforms of support in localities throughout Scotland. In each of our localities, which mostly follow local authority boundaries, our goal is to provide funding for a central Dementia Resource Centre, a Dementia Advisor, a Community Activity Organiser and a Volunteer Co-ordinator.

Community
Connexions

Memory
Walk

Membership



**Dementia
Advisor**



**Access to
PDS
Link
Worker**



**DRC
Local
connection
point
Helpline**

Carers
Support

SDWG

Dementia
Cafés

NDCAN

Creative
Practice



Alongside this, in some areas we are also funded by the local Integrated Joint Board to provide Post-Diagnostic Support Workers or Link Workers and registered Day Services.

In many areas we have been able to put this full range of support in place and it is truly remarkable to see the impact that this can have. People are linking in with our Dementia Resource Centres for information and advice; they are meeting with our Dementia Advisors and getting help on all aspects of dementia, from getting a diagnosis to choosing a care home. For many, the range of community activities that are on offer is helping them maintain contact, connections and friendships, and to avoid the isolation and loneliness that is too often a common feature for people living with dementia. Carers are also developing peer support networks and using these resources to keep connected and to feel better supported. Many volunteers are stepping up

and manning our Resource Centres; helping out at groups or in our Day Services; and many others are providing direct support and connections to people in their own home and care homes. It is so important to let people know that we are there for them throughout their whole journey living with dementia, and we are committed to making this a reality. The massive number of people who have signed up to be Dementia Friends, over 50,000, in itself tells a story that our communities in Scotland want to do their part to help.

The diagram above shows you how we aim to be there for people with dementia and their families, and we are making great progress towards this. All of the 32 local areas have a Dementia Advisor in place, in recent years we have opened up 16 new Dementia Resource Centres, we now have 29 Community Activity Organisers and 10 Volunteer Co-ordinators.



At present we are also commissioned to provide Post-Diagnostic Support Link Workers in 22 areas and we have registered Day Services in all but 15 areas. Although not funded by us, this support is a key element to the local infrastructure and a core part of delivering the National Dementia Strategies. For us, the opportunity to provide highly skilled therapeutic work at the point of diagnosis, and in the later stages, is essential in delivering our aim of supporting people from the beginning to the end of their time living with dementia.

At the heart of our localities are people with dementia and their families, our members and activists. We have been developing a strong collective voice with these groups in order to push for local action on the National Dementia Strategy. The investments we are able to make fill a vital gap, but we must continue to ensure that the right funding and support is being directed towards all aspects of dementia care in our health and social care services.

We need at least £100,000 in each of the 32 local areas to sustain or create this platform of support, this is the main role of our Community and Events Fundraising Team and local staff. They have been doing very well; coming from having no Dementia Advisors in 2009 and no Dementia Resource Centres we have made some remarkable progress and we are indebted to all who have helped us so far.

Our aspirations and plans are quite clear, but there is much work still to be done. We truly believe that these types of support and this local platform will help many people avoid being on their own, isolated and disconnected. It is the basis from which people can live well with dementia and continue to live within their community for as long as possible.



More info

Visit www.alzscot.org/daw to find out the many ways you can help us to make our vision a reality this Dementia Awareness Week.

Inter-generational experiences of dementia

By Robbie Gardner, 6th year pupil at Coltness High School, Wishaw

All cards on the table, I'm 17 years old and before Henry Simmons asked me to do this article I only knew the very basics of dementia. It began when I went into Glasgow to meet with Kirsty Yanik, who gave me a summary of all the good work Alzheimer Scotland do. Kirsty informed me about the 'Green Hands Together' project which takes place in my local area. It is a very worthwhile project which brings together young children and those living with dementia to build a sensory garden.

Later I was invited to a meeting with Kevin Black, who works in the Bridgeton Resource Centre. He gave me a rundown of his duties and explained what the centre is used for. Sometimes people stop by just to ask one question whereas others, both people with dementia and family members, use it for more long-term support. Kevin also gave me more information about the work the charity does in the local

community. Alzheimer Scotland run memory groups which are tailored to the needs of the community. In our area they mainly focus on football, but in other places they may have groups that reminisce about rugby, for example. It is all very area dependant.

Kevin also told me about a very inspirational man, Henry Rankin, who has shown that life doesn't end with a dementia diagnosis. This is the message that Alzheimer Scotland is trying to promote. Encouraging those with dementia to continue on with their lives because, as daunting as a diagnosis is, life carries on for them and their loved ones.

Overall, this taught me that dementia awareness in schools isn't what it should be. I've been in high school for six years now, but not once have I had an assembly or even a guidance lesson on dementia. There is plenty on heart disease, which of course is still a big issue, but surely more time can be spent on a disease which affects 90,000 people in Scotland alone. We don't fully know all of the causes of dementia, which



makes it all that more scary that schools don't discuss it with students. Maybe after I've left school more dementia awareness assemblies will occur or it will be discussed in guidance classes but at this current moment in time it is heavily underrepresented.

Alzheimer Scotland, through projects like 'Green Hands Together', aims to tackle the lack of dementia awareness in schools. This for me is increasingly important, particularly as it is young kids they are working with. By learning about dementia at a young age, there is a better chance of them retaining this knowledge and some may end up educating their parents a little bit. This project is a step in the right direction and I can only hope more like it appear in the future. Personally, I would like to see more projects aimed at raising awareness amongst high school students as well.



Green Hands Together project in Wishaw

More info

Would you like to know more about the work we are doing to raise awareness of dementia in schools? Contact your local Dementia Advisor by visiting www.alzscot.org

War and Peace – my diagnosis story

By Geoff Orry, Scottish Dementia Working Group member

These few words are a reflection of my life over the past ten months, coming to terms with my diagnosis of dementia. My desire is that they will offer hope and encouragement to people who have recently been diagnosed and are looking for some light at the end of a seemingly very long and dark tunnel.



I have titled this article 'War and Peace'. The 'war' refers to the war that was raging within me while I was coming to terms with my vascular dementia diagnosis. The 'peace' is the calm and tranquillity experienced in the company of my dear wife, Anne, who is also my carer.

For many months (years!) I ignored what turned out to be the early warning signs of dementia. I always strongly 'poo-pooed' suggestions from my lovely wife to visit our GP and get advice about memory loss and balance problems.

Eventually I did visit my GP. He performed some standard NHS memory tests and I was referred for an urgent appointment at the Vale of Leven Hospital in Dumbarton for a diagnosis. Eventually I was diagnosed with vascular dementia. Initially my reaction was one of shame; I just wanted to keep my diagnosis secret from friends and neighbours. During the first few months post-diagnosis I was more irritable than usual. I was still in denial mode and in general a very bad tempered 75-year old. How my dear wife put up with me, I have no idea!

The shock of realising that there was no cure for dementia and that driving was no longer an option was devastating, and I had many questions. Fortunately, the internet is a great

source of information. However, the credibility of the sources you use is critical. I access only NHS websites or the Alzheimer Scotland website.

Since being diagnosed, organisational skills are where I need the most help from Anne. She organises my diary for SDWG meetings and does most of the telephoning for me. I have also started to use speech recognition software for the dictation of emails and documents. This has the advantage of forcing me to concentrate on getting the right words

"one of the highlights of my post-diagnosis experiences has been the invitation to join the Scottish Dementia Working Group."

out in the right order.

One of my biggest problems was lethargy and a lack of motivation to engage with my two hobbies: building model aircraft and watercolour painting. I've also recently repaired the boundary fence between my driveway and our neighbours after it blew down during a storm. This was hard work, but it was very therapeutic and helped me overcome lethargy.

Local authority support for dementia in East Renfrewshire is first class. Blue badge and attendance allowance, adjustment to council tax and so on were all arranged by home visits or a visit to their office. All the information supplied was clear and concise with virtually no 'red tape'.

I attend 'Memory Lane' sessions twice a month. This is a group for people in the area who have been diagnosed with dementia; it's great fun and is run by volunteers mainly from local churches. One of the highlights of my post-diagnosis experiences has been the



invitation to join the Scottish Dementia Working Group (SDWG). My morale was lifted when I received the invitation to join the SDWG and the immense boost I felt cannot be measured. Here I was meeting other people diagnosed with dementia: some were displaying similar symptoms as myself while others were farther down the dementia path than I, but they were all leading energetic normal lives. I can also boast that they are a friendly bunch who enjoy a bit of banter at the regular meetings. The feeling that I was making a contribution to such a worthwhile organisation was indeed, very, very rewarding.

More info

Find out more about the Scottish Dementia Working Group at www.alzscot.org/sdwg

Scotland international rugby player becomes a Dementia Friend

By Nicole Nayar, Information Manager

Henry Pyrgos, 28, has joined Alzheimer Scotland as an ambassador by becoming a Dementia Friend.

The former Scotland captain left his chemistry degree at Loughborough University after being offered a spot in the Glasgow squad at the end of his second year.

"I had a big decision to make, well, at the time it felt like a big decision. I always knew I wanted to play sport though. Even when studying, my goal was always to play rugby."

Coming from a family of teachers, Henry began playing Scottish age group

rugby and, despite growing up in Dorset, was able to play for Scotland due to his mother's Dundonian upbringing.

"Coming through age group rugby made the choice to move to Glasgow much easier. I was leaving my life and my friends down south, but I already knew a lot of the guys at Glasgow because of that."

Henry is currently completing an Open University degree in Business and Environmental studies and has experienced the strains of balancing university with his sporting career. "We do get some time off from training during the week, but mentally it's been quite challenging juggling rugby and completing my studies."



Name: Henry Benjamin Pyrgos
Date of birth: 9 July 1989
Club: Glasgow Warriors
Position: Scrum-half
Caps for Scotland: 27





Photo credit: Craig Watson

Outside of his rugby career, Henry was married last summer and lives with his wife in Glasgow. "I love sports. Although we aren't allowed to play a lot of sports in case we get injured, I watch a lot of NFL and play golf whenever I can."

For Henry, one of the worst things about living in Scotland for the past eight years has been being apart from his family. "My grandad, Nick, has Alzheimer's disease and it's been hard being away as I haven't been able to see my grandparents as much as I'd like."

"I saw the opportunity to get involved with Alzheimer Scotland and it just seemed like a great choice for me. I have always been so close to my grandparents so it's been nice to learn a

lot more about dementia and what they are going through at the moment."

"Even learning things like the difference between the types of dementia has been great. You hear about dementia and Alzheimer's in the news but you never get a proper explanation about the differences."

"My grandma was struggling to cope as my grandad's full-time carer, so they have made the decision to move into an assisted living home."

"I definitely feel more aware of dementia and I have been chatting to my dad about it as he looks after my grandad quite a bit. It's been nice, members of the family and people at training have been asking me about it."

"There's a lot of guys in the squad whose grandparents have dementia and

the stigma around it has definitely been reduced. More people are talking about it, which is great!"

"I would definitely tell other people to get involved with Alzheimer Scotland and become a Dementia Friend. I am looking forward to finding out what else I can do to help through my role with Alzheimer Scotland. The more you learn about it the more you can help people out."

More info

Would you like to become a Dementia Friend? Visit the Dementia Friends Scotland Website to find out more www.dementiafriendsscotland.org



Be heard!

Your **voice** matters!

We need to hear about your experiences of dementia care and support in your local area.

Visit

www.alzscot.org/campaigning/get_involved
to find out more.



Can you help us make sure
nobody faces dementia alone?

Text **WISH29 £5** to **70070**
To donate £5 to Alzheimer Scotland

Text service provided by Vodafone UK. For full T&Cs please visit www.justtextgiving.vodafone.co.uk

Diet for the Mind by Dr Martha Clare Morris

By Nicole Nayar, Information Manager

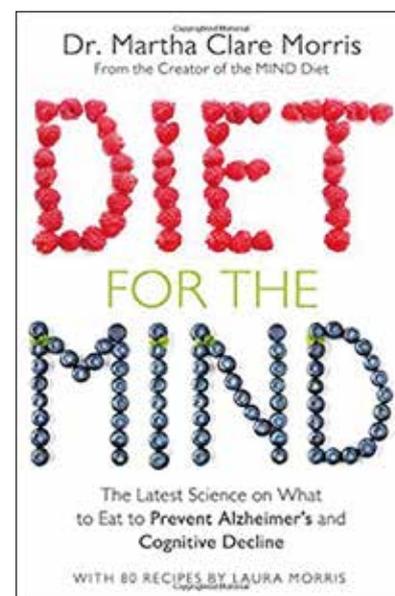
A study published by Dr Morris in 2016 showed that the MIND diet lowered the risk of Alzheimer's by as much as 53 per cent in participants who adhered to the diet rigorously, and by about 35 per cent in those who followed it moderately well. The MIND diet is a hybrid of the Mediterranean and DASH (Dietary Approaches to Stop Hypertension) diets and has 15 dietary components, including ten 'brain-healthy food groups' and five unhealthy groups.

Diet for the Mind is an easy to read book with lots of practical advice and ideas. Dr Morris is careful to include a number of references in her book, backing up the advice with peer-reviewed research.

The latter part of the book contains suggestions and recipes for putting into practice the lifestyle and dietary changes recommended by the author.

These recipes are simple, easy to follow and the images in the book look delicious.

If you're looking for some science-based advice on what to eat (and what not to eat) to promote brain health then this book is definitely worth a read.



More info

Have you read a great dementia-related book recently? Would you like to share your thoughts with our readers? Email info@alzscot.org for more information on how to become a guest reviewer.

Get Involved – with fundraising!

By Michelle McDonald – volunteer in Midlothian

What attracted you to volunteering for Alzheimer Scotland?

I really enjoy volunteering; my passion comes from the fact my dad died of Alzheimer's disease aged 64. I like to get out there and promote awareness of the charity. I especially enjoy helping people with dementia and their families.

Tell us more about your role as a volunteer.

I do a lot of event volunteering, giving people information about the charity and helping to make people aware of the support available to anyone affected by dementia. I also volunteer when I can in the Bonnyrigg Bungalow Day Centre, supporting people with dementia directly in the local community.

Why should new volunteers join us here at Alzheimer Scotland?

You'll experience a real feeling of satisfaction and positive self-worth from giving something back to the community. It's also very rewarding helping a charity that is reliant on volunteer time.

Finally, what's the funniest moment you've had volunteering? What's the thing that always makes you smile?

Our mascot Buddy and I get on very well. He's always up to tricks and we have lots of fun together out and about volunteering. My favourite moments are definitely when he misses high fives and tries to eat treats when he's not supposed to. He can be very cheeky and people love him!



Michelle McDonald and husband

More info

Could you give up a day to be a Memory Walk volunteer? Find out more information at memorywalkscotland.org/volunteer

Memory Walk

By Leah Cranney, Memory Walk Fundraiser

Memory Walk is back for 2018 and it's promising to be the best year yet. Have you ever taken part in a Memory Walk? If not, here are some of our lovely walkers from last year's Fife Memory Walk to tell you why you should join them in 2018...

Michelle Pullar

Myself and my two sons (aged seven and one) are doing the Memory Walk again this year, as a number of family members have been affected by dementia. My Di (grandad) died just over two years ago and his brother, my great uncle, died in June last year. Both of them had vascular dementia. My gran also has dementia and I'm watching it become more advanced. People always think dementia is just people forgetting things, but it is so much more than that. After experiencing dementia with three family members, I would never wish it upon anyone.

I hope we can raise enough money so that no one faces dementia alone or, better still, that a cure can be found to end this disease.

My sons and I regularly walk around Lochore Meadows. Having a busy life, it's important for me to spend some time away from the hustle and bustle, and the scenery around that walk

is beautiful. Lochore Meadows was always a place my family members with dementia loved, so it makes it all the more special.

"Anyone thinking about doing this walk should not hesitate."

Anyone thinking about doing this walk should not hesitate. It's suitable for people of all fitness levels and also suitable for pushchairs. The scenery is amazing and, whether you have been affected by dementia or not, it's a fun afternoon with activities for kids. Most importantly you are raising money for an incredibly worthwhile cause.



Michelle and boys - after walk





Ann McMonigle

In March 2015 we lost a valued member of our family: John, who lived with dementia for 8 years. John was a much-loved husband to Marion and father to Ann, Ian and Derek.

During the time that Dad was ill, Mum looked after him on her own, it being the duty of a loving wife, as she saw it. She was never aware that she could get any help, nor did she actively seek it out. She just did what she had to, not wishing to burden the rest of the family.

When the first Memory Walk fell on what would have been Dad's birthday, we decided that we would do it in memory of him, and have continued

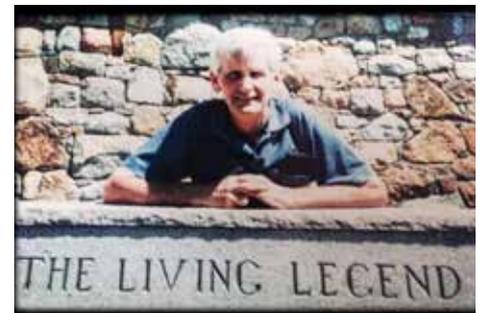
"We would encourage you to come along and have a go – no training necessary!"

doing this every following year. We have since found out that several other members of our family have had a diagnosis, so now we do the walk for all of them. As a family, we use the walk to reflect and remember, thinking about Dad and how he would have enjoyed it. He did love his walks, especially doing it

as a family. Mum is in her eighties now so we go at a pace that suits her and she enjoys it.

We do this walk to raise funds, and to increase awareness of this disease; to further research in the hope that one day a cure can be found so that other families will not have to go through this.

We would encourage you to come along and have a go – no training necessary! Make it a family outing, bring a packed lunch, bring the kids, bring your dog! It's great exercise for you all. Take the walk at a pace that suits you, take in the scenery and, most importantly, enjoy it!



Ann McMonigle's dad

More info

Sign up for your local Memory Walk today at memorywalksscotland.org

Memory Walk 2018

Aberdeen

30/09/2018

Angus

01/09/2018

Ayrshire

09/09/2018

Glasgow

30/09/2018

Borders

08/09/2018

Dumfries

23/09/2018

Dundee

09/09/2018



East
Dunbartonshire

01/09/2018

Fife

16/09/2018

Forth Valley

16/09/2018

Highland

02/09/2018

Inverclyde

23/09/2018

Lanarkshire

22/09/2018

Midlothian

23/09/2018

Perth

16/09/2018

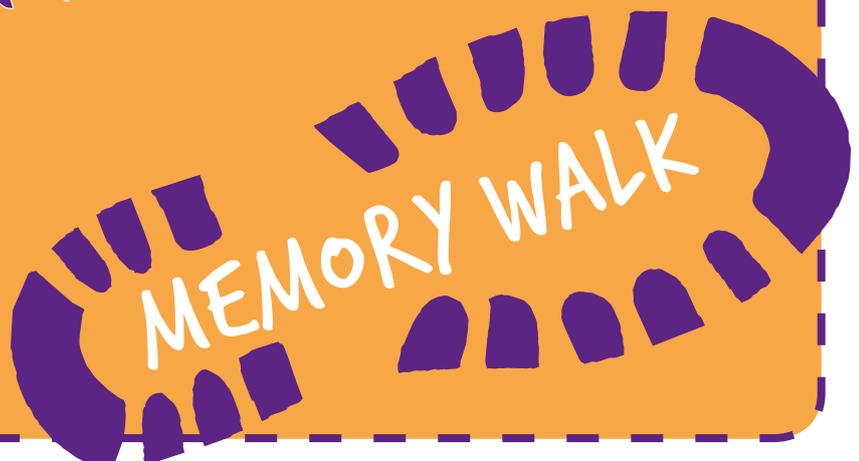


"Anyone thinking
about doing this walk
should not hesitate"

Michelle

Sign up for your local
Memory Walk today at

memorywalksscotland.org



The Big Pedal – cycling for dementia

By Charlotte Lowry, Senior Anti-Money Laundering Investigator at HSBC

I'm Charlotte Lowry, 26, originally from rural Dumfriesshire but now living and working in Edinburgh. I work in AML (Anti-Money Laundering Investigations) at HSBC bank and in September 2017 I jumped on my bike and cycled from Dumfries to Birmingham in aid of Alzheimer's and dementia.

I was not an avid cyclist. I did not own a bike. I did not have a particular urge to cycle half the country. But what I did have was an intense personal connection to the devastation that can be caused by Alzheimer's and dementia. My grandmother had vascular dementia and my grandfather had Alzheimer's. I also have many friends who have had their own difficult experiences with these illnesses.

At the start of June 2017, the 'The Big Pedal – Road to Birmingham' was announced. The challenge was a cycle to Birmingham from each of the main regions of HSBC UK: Scotland, (Dumfries), the West (Cardiff), South (London) and East (Sheffield). I was awarded a spot on Team Scotland despite answering 'no' to the question 'do you own a bike?' on the application form. However, what I did emphasize was my huge desire to stand up and do something for such a personal cause.



I had never done anything like this before. I had received bikes as Christmas presents as a child but swiftly traded two wheels for four hooves and spent my childhood riding horses. At university it was netball, skiing and ultimate frisbee (which is a real sport) but never cycling. However, something in the challenge struck a chord with me, and I couldn't wait to get started.

A week after finding out I had a spot on the team, and nine weeks before the challenge commenced, I went out, bought a bike and walked it home for fear of sitting on the thing. The next weekend I put the bike in my car (after having to facetime my dad and have him precisely explain how to take the back wheel off) and drove to Dumfries, which was to be my primary training location.

"I was awarded a spot on Team Scotland despite answering 'no' to the question 'do you own a bike?'"

This was to be my weekly routine. My dad became my number one training partner. As a recent retiree, it got him back out on his bike and boosted both of our fitness levels. I would spend many rides with a variety of training partners, but my dad will always be number one.

My training could not be described in any other way than steep. It took a while to become accustomed to long distance cycling. I was forced to overcome my first long ride totally by accident when I got lost on what should have been a 30 kilometre route. I ended up 35km away from where I intended to be! I was spurred on for the last 10km home thanks to a surprise £50 donation from my friend Scott which gave me an energy boost as good as any of the energy gels I was consuming! I soon eased in to regular long rides and I embraced the whole cycling lifestyle with clip shoes, my beloved Garmin and an array of lycra.

While most of my training was done with my dad or solo around rural





Dumfries, the main challenge was definitely a team ride. 'Team Scotland' consisted of seven other riders, hailing mainly from across Scotland, including a few of us based in Edinburgh. But we also had two riders from Birmingham join us on the Dumfries start line. This meant that the first time we rode together as an actual fully-fledged team was on the start line.

"Team Scotland raised over £20,000 for Alzheimer Scotland, an unbelievable feat."

Luckily for me, I was able to get support from my knowledgeable Edinburgh based teammates for rides, lunches and even velodrome days. As the newbie of the team, having experienced riders around me was totally invaluable but also petrifying. When you ask somebody who you are going to be cycling over 400km with when they started cycling and they reply 'I don't remember ever not cycling' it is a little daunting. Fortunately, they were all equally supportive and encouraging.

I tried to refocus all my fear into fundraising and raising awareness to highlight the reasons why I took

on this challenge. In terms of raising vital funds, I pestered and hounded my friends and family, held bake sales and a raffle. My little brother even managed to win himself a Chris Hoy signed jersey. As a whole, Team Scotland raised over £20,000 for Alzheimer Scotland, an unbelievable feat. Combined with all other regions the total was nearer £70,000.

The cycle itself was three days long, over 400km and included some intense climbs. Along the way we met strangers in cafés and other cyclists on the road. Everybody was eager to hear about the challenge and lend words of wisdom. We got supportive beeps from cars and children yelling "you can do it" from school playgrounds. We were more than just a cycling team, we were a group of people with a connection to a cause who bonded forever.

I would do it again in an absolute heartbeat. I now adore cycling, I am a member of a local Cycling Club and regularly head out on rides or down to the local cycling shop for a coffee. As personally rewarding as the ride was, the greatest part about the challenge was the funds and awareness raised to help support the amazing work done by Alzheimer Scotland on a daily basis.

When I began writing this article I asked those closest to me what I should write. My family are predominantly based in Northern Ireland and this is where my

grandparents experienced the illness. However, my Aunty Liz was keen to highlight the immense support they received from Alzheimer Scotland through the tools and information available on the website. She noted that she found it useful when she needed explanations for some of my grandad's behaviour and what exactly the difference was between my granny's vascular dementia and my grandad's Alzheimer's. She also wanted to emphasize the importance of family.

In many cases, the occurrence of dementia highlights the strength of a family unit. This is very much the case in my own experience. This is an illness that takes its toll on both the person and those who love them the most. But the disease never wins as long as there are people willing to (sometimes literally) pedal it out into the world to raise money and awareness. This is supported by the great work done by Alzheimer Scotland and I hope the money raised from this challenge can benefit as many people as possible.

More info

Has Charlotte inspired you to get on your bike and challenge dementia?
Visit www.alzscot.org/fundraising/events/sponsored_events to find out what events we have going on this year.

Dates for your diary



May 2018

Sun 6 May	Glasgow Ladies Lunch
Wed 9 May	Open Door Event at Shetland Dementia Resource Centre
Mon 14 May	Open Door Event at Aberdeen Dementia Resource Centre
Sun 20 May	BHGE 10K
Wed 23 May	Open Door Event at Fife Dementia Resource Centre
26–27 May	Edinburgh Marathon Festival

June 2018

Sat 2 June	It's a Knockout
Sun 3 June	Aberdeen Kiltwalk
Fri 8 June	Alzheimer Scotland Annual Conference 2018 at the EICC, Edinburgh
Sun 10 June	Great Woman's 10k
16–17 June	Zipslide across the Clyde
16–17 June	Tough Mudder Half/Full
Mon 18 June	Open Door Event at Kilmarnock Dementia Resource Centre

July 2018

Sun 1 July	Rotary Club of South Queensferry Abseil
22–23 July	Spartan Race
Sat 28 July	Glasgow Big Fun Run

For the most up-to-date information on our events visit www.alzscot.org.



This Dementia Awareness Week help us make sure nobody faces dementia alone.



**Alzheimer
Scotland**
Action on Dementia

DEMENTIA
AWARENESS
WEEK

4-10
June

Help us to raise awareness of dementia
across Scotland.

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Find out more: www.alzscot.org/daw

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