

Dementia in Scotland



Spring 2019 – Issue 98



Prevent now
Care today
Cure tomorrow

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Welcome

Welcome to this edition of Dementia in Scotland, where we look forward to a busy 2019. As our readers will know we aim to make sure nobody faces dementia alone. We do this by providing as much direct support as we can and by campaigning for the rights of people with dementia and their families at every level in our society. In this current turbulent and uncertain world we live in we find ourselves, more than ever, having to campaign for these rights and for fair treatment of everyone living with dementia.

That is why we established the Fair Dementia Care Commission, bringing together a small group of experts to help explore why people with advanced dementia have to pay so much for their care costs in contrast to other illnesses. The Commission was led by Former First Minister Henry McLeish and it concluded that people with advanced dementia are being treated unequally, as it is quite clear that their needs are healthcare needs and should therefore be free at the point of delivery. The report - Fair Dementia Care for People with Advanced Dementia, launched at the end of January. In our view this is one of the most important policy reports we have published. There are many reasons as to why people with advanced dementia find themselves in this unfair position and the report looks at these in detail. However, no matter how this position has come about, it cannot continue. We must bring an end to this inequality and we have asked the Scottish Government to look carefully at the findings and fully implement the recommendations.

We have embarked on a campaign to gain as much public support for this as possible and you can read more about the report on pages 26 and 27.

We are moving in to an extremely busy and exciting time, with plans fully underway for this year's Dementia Awareness Week which runs from 3 - 9 June. This year we are focussing on the importance of research, as well as sharing the support we offer across Scotland to help people live well with dementia. On pages 18 and 19 you can read more about what this messaging means to you. Alongside Dementia Awareness Week comes our Annual Conference, which will be held at the Edinburgh International Conference Centre on Monday 3 June. Whether you're a regular attendee or have never been before, pages 20 and 21 will tell you what to expect on the day.

2019 is shaping up to be another really busy year for Alzheimer Scotland. Thank you to everyone who is involved in helping us make sure nobody faces dementia alone - I look forward to working beside you all in the upcoming months.



Henry Simmons

Henry Simmons, Chief Executive

We would love to hear your thoughts on Dementia in Scotland magazine. If you have any questions or comments, get in touch with the editor Dawn Ferguson by email: dferguson@alzscot.org or by phone: 0141 410 0108.

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.

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Alzheimer Scotland's Freephone Dementia Helpline is open 24 hours a day, 365 days a year.

If you need information or emotional support call 0808 808 3000 or email helpline@alzscot.org at any time, day or night.

Thanks to the Dementia Helpline team, nobody has to face dementia alone.

24 HOUR

**Alzheimer Scotland**
Action on Dementia

Dementia Helpline

Freephone 0808 808 3000
Email helpline@alzscot.org



Building international relations

By Jan Beattie, Deputy Director of Workforce Development, Alzheimer Scotland



In February, Alzheimer Scotland was invited to Japan to play a lead role in a series of events hosted by the Health and Global Policy Institute (HGPI). Based in Tokyo, the HGPI are a think tank who influence and shape policy at government level and have a wide reach both within and beyond Japan.

Myself and my colleagues Jim Pearson and Lindsay Voigt were hosted by HGPI to present at the Japan-UK-Australia global expert meeting on creating dementia-friendly communities; to lead a round table discussion on our approach and to meet with the Japan Dementia Working Group.

Jim gave the keynote presentation on our rights-based approach and our policy development; an excellent presentation that set a very high bar for colleagues from Australia and Japan to follow.

The Japanese government has funded HGPI to investigate how to implement our 5 Pillar model of Post Diagnostic Support (PDS) and Lindsay shared how the model supports her person-centred PDS practice, using a case study example to connect the audience to our PDS work.

I talked through our vision for localities. Our ambition is to make sure Alzheimer Scotland stays with people throughout their dementia, no matter where they stay in Scotland.

Representing Alzheimer Scotland in Japan is quite an experience; our reputation couldn't be better and people from government, service providers, students and people working in health and care are so keen to learn from us. This was particularly true when we had the privilege of meeting with the Japan Dementia Working Group who have taken the

lessons from our own Scottish Dementia Working Group (SDWG) to establish their own campaigning approach. Unlike here, the absence of a national organisation supporting the Japanese group results in it having significant struggles to make the same impact that the SDWG has in Scotland.

The cultural and health and social care system differences between Scotland and Japan mean that our approach and progress will take time to be translated to fit Japan, its expectations and its ways of working. It was a great opportunity to be able to play a small part in that and to represent Alzheimer Scotland on a global stage.

Alzheimer Scotland welcomes the opportunity to share practice on an international scale. For more information, contact Susan Rendell by email: srendell@alzscot.org or by phone: 0141 410 1178.



We sing, you dance

By Dawn Ferguson, Content Manager, Alzheimer Scotland



When Lesley Cumming, West Dunbartonshire's Community Activities Organiser, heard that Scottish Ballet were inviting people across Scotland to submit wishes to help them celebrate their 50th birthday celebrations, she knew it was too good an opportunity to miss. So, late last year she submitted a wish for the Every Voice Community Choir to perform with them, not thinking that anything would come of it.

Over 400 wishes were posted online, with more than 100,000 votes cast by the general public, before the top 50 were presented to a judging panel including Dame Darcey Bussell, Susan Calman, Fred MacAulay and Janice Forsyth.

Thanks to Susan Calman, comedian and star of BBC's Strictly Come Dancing, the Every Voice Community Choir were championed to be one of the five successful wishes and in late January dancers Constance Devernay and Jamiel Laurence visited the choir to reveal that Scottish Ballet would work with them to create a unique performance for

their community event; bringing their wish of 'We Sing, You Dance' to life. In addition, Scottish Ballet will continue working with the choir, inviting the ensemble to perform on stage at a performance of The Snow Queen in Edinburgh in December.

Lesley Cumming, said: "I am over the moon that our community choir has been granted this wonderful wish to perform with Scottish Ballet as part of their 50th anniversary celebrations later this year. Thank you to everyone who has supported us, and all those who voted for the Every Voice Community Choir. The day will be magical for all involved; a once in a lifetime memory."

For more information about Scottish Ballet, and the Five Wishes campaign, visit: www.scottishballet.co.uk/wish. To find out more about the Every Voice Community Choir, contact Lesley Cumming by email: lcumming@AlzScot.org or by phone: 0141 410 5304.

Celebrating our youth

Alzheimer Scotland is very lucky to benefit from the support of people from all age groups. However, it's always a pleasure to hear about the motivation of our more youthful supporters like Iggy and Lily.



By Elaine Nixon, PR Manager, Alzheimer Scotland

One of our young fundraisers recently visited the Palace of Westminster to be honoured for his kindness and compassion at the annual British Citizen Awards.

Six-year-old Iggy Just received a British Citizen Youth Award and was presented with a special medal by Ashley Banjo of Diversity in recognition for being a young carer for his grandad, who is living with Alzheimer's disease.

As well as caring for his grandad John Collins, age 71, Iggy has undertaken fundraising for Alzheimer Scotland and completed a 5K walk raising £650.

Though only six, Iggy helps to look after his grandad by playing, drawing and singing songs with him and making sure he's safe. Due to cognitive impairment his grandad had forgotten how to take medication but with Iggy's prompting, he now manages to take his vital medication correctly.

Well done Iggy, we're so proud of you!

By Dawn Ferguson, Content Manager, Alzheimer Scotland

When nine year old Lily Kermack visited her great-grandparents in the summer last year, it inspired her to support Alzheimer Scotland. Proud mum, Lynsey, wrote to Alzheimer Scotland to tell us about Lily's amazing fundraising.

'In the school holidays last year, Lily and myself popped in to visit my grandparents; Lily's great-grandparents. My nana has vascular dementia and was having a challenging morning when we visited which prompted some questions from Lily. I explained what was happening to nana in more detail than we had originally told her when we received the initial dementia diagnosis a few years ago.

A week or so later, she approached me to say that she wanted to hold a summer bake sale, with all proceeds to be donated to Alzheimer Scotland.

Lily came up with the idea, planned the day, designed advertising materials and baked the majority of the cakes all by herself. The bake sale was held last August and was planned around the gorgeous summer weather we had been having however, typically, it poured down all day. Despite this, it was an amazing day and she raised £148.82 which she was so pleased with.

For a nine year old to have identified a way to help a charity and then plan, design and execute an event, it makes us so proud of her. There's no doubt that her determination was driven by love for her nana.'

//

I really enjoyed planning the fundraising, and the support from my family and friends was great. It was brilliant fun!

//



Celebrating nearly 1000 Dementia Champions

By Dawn Ferguson, Content Manager, Alzheimer Scotland

93 students from the ninth cohort of health and social service Dementia Champions graduated on Wednesday 13 March, bringing the total number of graduates since the programme began in 2011 to 950. The latest cohort boasts representatives from 12 health boards and 15 social service organisations across Scotland.

The national conference and graduation event is hosted in partnership by NHS Education for Scotland (NES), the Scottish Social Services Council (SSSC), Alzheimer Scotland and the Scottish Government.

The Dementia Champions programme is part of the NES and SSSC Promoting Excellence workforce development programme. This programme supports the implementation of the national knowledge and skills framework for staff working with people with dementia, extends the reach of workforce learning and training opportunities and supports improvements across Scotland's Dementia Strategy priority areas.

This event is focussed on the commitments set out to improve the experiences and outcomes of care for people with dementia who require care and treatment in hospital settings, including support on their discharge and end of life care.

Minister for Mental Health Clare Haughey said:

"I am delighted to support the Dementia Champions programme and recognise the importance of improving the care and support for people living with dementia and their families and carers.

"Supporting and developing the dementia workforce across health and social care remains at the heart of so much of our National Dementia Strategy - and it's important to recognise and celebrate the commitment of front-line staff and managers."

Henry Simmons, Alzheimer Scotland Chief Executive, said:

"Our Dementia Champions programme is an excellent example of our partnership working with NHS Education for Scotland (NES), the Scottish Social Services Council (SSSC) and the Scottish Government, to transform and improve standards of dementia care in hospitals throughout Scotland.

"We are delighted to recognise the ninth cohort of graduates who have all made significant contributions to support those living with dementia within their communities. Our highly skilled Dementia Champions all share with us a deep desire to ensure that the best

possible quality of care and support is always delivered to everyone with a dementia diagnosis and their families. At a time when our health and social care system is under increasing pressures, it is extremely reassuring to see the commitment of all those graduating today and the dedication they have shown to improving the experiences of people with dementia and their families."

NES and the SSSC have taken forward several initiatives to support improvements in the care of people with dementia in acute general hospitals, community hospitals, specialist dementia units and related social service settings. This includes the development of a range of learning resources to support implementation of the Promoting Excellence Framework, various training programmes and joint working with other partners to support improvements.



Supporting our communities

Kelso Dementia Resource Centre

By Joyce Gray, Deputy Director of Development, Alzheimer Scotland

Our Kelso Dementia Resource Centre officially opened on Friday 18 January and is the latest centre to reflect the latest best practice in dementia-friendly design and to ensure they offer the best possible environment for delivering support in Scotland's communities. The centre, located on Bridge Street, will serve as a community hub to support and connect people living with dementia and their carers and families across the Scottish Borders.

Provost Dean Weatherston joined Alzheimer Scotland's Chief Executive Henry Simmons and local carer Jim Sykes to officially open the new centre along with resource centre staff, local volunteers and people living with dementia and their carers.

Previously offering supports from Kelso Community Hospital, the newly established Alzheimer Scotland Dementia Resource Centre aims to bring dementia to the high street by providing a stimulating and sociable environment for people living with dementia, their families and carers to access information, advice and support.

The new design of our Dementia Resource Centres follow the principles of dementia friendly design, but in a way that allow for a range of individual experiences within the environment. The people who visit our centres vary from people who may have just received a recent diagnosis, to those who might be living in residential accommodation as well as families and carers, so a range of needs must be accommodated. We wanted to make accessible and understandable social settings for people to feel comfortable in.

Within our design principles we strive to ensure that there is a local feel, which helps to make people feel at home and that they belong. A sense of homeliness is important – and can be conveyed through appropriate scale and finish.

Specifically we take care to:

- Avoid complicated pattern and colour mixes
- Avoid encoded cues that have to be learned
- Consider cues that are more intuitive (better for long term memory)
- Avoid complicated changes of direction, like doors
- Consider sound, light, and contrast as part of the sensory mix.

Our Dementia Resource Centres reflect this considered approach to design, and we hope that they will be the benchmark of good user-centric buildings, that can host innovative supports for many years to come.



If you would like to know more about the design principles applied to our Dementia Resource Centres contact Joyce Gray by email: jgray@alzscot.org or by phone: 0141 410 1065.

The day a wish came true

By Connie Sinclair, Support Worker, Alzheimer Scotland

Last January, we created a 'wishing tree' for staff and people with dementia who attend day care to hang their wish for the coming year.

The wishes varied from "go out for tea and cakes" to "lose 20 lbs." Then, beside them, hung David's wish: "to be a rag and bone man." Every time "rag and bone man" was mentioned, David's face would light up and we knew it had to happen.

The smile on David's face was priceless!

With the help of a local husband and wife, Eddie and Elaine, and their horse Henry, we were able to make this wish a reality. David and his wife Lesley spent a beautiful sunny afternoon travelling through local country lanes whilst sitting on a cart with Henry.

When we got back to the house Eddie put Henry away and Elaine came out with tea and cakes, which we enjoyed while sitting outside in the sunshine. A perfect end to a perfect day.

P.S. The 20 lb's? well, that's back on the tree for this year.



Dementia-inclusive sensory garden in Inverclyde

By Marie McEleny, Service Manager, Alzheimer Scotland

Inverclyde Dementia Resource Centre has been collaborating jointly with members of both the Caddlehill Allotments and Gardens and the local Duke of Edinburgh Award team to create a new dementia-inclusive sensory garden and walkway. There has been fantastic progress made so far on this project which will make a real difference to people with dementia.

Whether you are a green-fingered expert or an enthusiastic novice, this exciting new project will enable users to enjoy the outdoors, grow their own vegetables and hopefully make new friends. A number of studies highlight the benefits of therapeutic gardens and horticultural activities for people with dementia. Collectively, they demonstrate increased physical health and fitness with positive effects on mental health.

We'd like to thank everyone for their ongoing dedication to this project and we can't wait to see the people we support benefit from it.



Fond memories

By Annette Tait, Volunteer, Alzheimer Scotland

At the Aberdeen Dementia Resource Centre our 'Memories of years gone by' programme can stimulate memories and personal stories in many ways using references from music, television, adverts, local and international news, photographs, sport, fashion and much more.

We regularly hold sessions where we look back at the events which were hitting the headlines in a particular year. We discuss local and international news, hear songs from the singles and album charts and theme music from movies and television programmes. We show video clips of TV adverts from the time (which always seem to provide the most laughs!) and people are encouraged to share their own memories of the year with us – some have even turned up dressed in outfits from the period!

The sessions are for anyone with dementia and their carers, families and friends. The sensory mixture of sound, image and talk encourages group discussion. Feedback from the groups has been really positive and we always look forward to finding out what memories the next selected year generates.



Partnership working

By Jim Baird, Locality Resources Coordinator, Alzheimer Scotland

Crosshouse Hospital and Alzheimer Scotland have embarked upon an exciting new project to allow people with dementia who are staying in hospital to benefit from all the therapeutic activities, reminiscence work, dementia dog initiatives and technological tools that we have developed over the years, but in a hospital setting. In collaboration with the Alzheimer Scotland Dementia Nurse Consultant, Susan Holland, and the ward sister we have created our own mini Dementia Resource Centre in the hospital where staff and trained volunteers will welcome people with dementia for weekly sessions that mirror the work we have been doing in the community.

The health board will soon be investing heavily in the facilities in and around the ward and we will be on hand to help them develop the activity room following dementia-friendly principles, as well as introducing some of the technology that works well in this environment. The sessions run weekly for two hours with referrals made from the hospital staff to allow for the best possible results – we will be working closely to ensure that the outcomes achieved are in line with the 'What Matters to Me' document that each person comes into the ward with. We have had some great results and compelling stories from staff and relatives about the difference this is making to a hospital stay



– we are capturing pictures and videos of the sessions and emailing them directly to relatives and carers.

Susan Holland said: "The importance of providing therapeutic activities which encourage mental, physical and social stimulation and which also provide pleasure and meaning to people living with dementia cannot be underestimated. We are therefore delighted to be working in partnership with Alzheimer Scotland to improve outcomes for people with dementia through the introduction of social activity groups within Ward 5D at Crosshouse Hospital".

Alzheimer Scotland are proud of our work in local communities. For more information on what's available near you visit www.alzscot.org.



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

Email: info@alzscot.org

Web: www.alzscot.org

Our 24 hour Freephone Dementia Helpline:

0800 808 3000



@alzheimerscotland



@alzscot



@alzscot

... or if you'd rather a face to face interaction why not visit your local Dementia Resource Centre.

Making sure nobody faces dementia alone.

Coming into hospital – 5 key things

By Hugh Masters, Policy Consultant, Alzheimer Scotland

Coming into hospital can be a worrying time for anyone. If you have dementia, you may be particularly worried and anxious about staying in an unfamiliar place. You may also be unsure about what will happen during your hospital stay. The following information is designed to help answer some of the questions you may have about preparing to come into hospital and about what to expect during your stay:



1

What do I need to bring in to hospital with me?

The hospital will send you information about what you need to bring with you:

- Power of Attorney Certificate (if you have this in place)
- Your prescribed medications/medi-box
- Comfortable clothing and nightwear
- Toiletries
- Hearing aids or spectacles (it's helpful to label your spectacles with your name or initials and what you use them for i.e. reading or distance)
- Small familiar items that will help you to feel settled. For example, a family photograph
- A small clock and calendar to help you keep track of the date and time.

It is very helpful for staff to have written information about the things that are important to you. If you have a completed Getting to Know Me document please bring this into hospital with you. If you don't have one, you will be able to get one by visiting: www.alzscot.org/gettingtoknowme or you can ask a member of hospital staff to provide you with this.

2

How will I know who people are and how to find my way around?

The team of staff looking after you should introduce themselves to you when you come into hospital. Every staff member has a badge with their name and job title. This can help to act as a memory aid of who they are and what their role is.

A staff member will show you around the ward area on admission. Clear signs will also be in use to help you find your way around and you will not be moved to a different ward area unless this is discussed with you, is needed as a result of your condition and is for your own benefit.



Photo courtesy Scottish Government

3

Will my family and friends be able to visit?

Scotland has a policy of open wards and all health boards are moving towards this.

Visiting times should be open and flexible to both your needs and those of your close friends and family members.

Family members and/or close friends will always be welcome to help you during your hospital stay if this is something you would both like e.g. help at mealtimes, with personal care or supporting you in discussions about your care.

4

Will staff know I have dementia and how to help support my individual needs?

If you would like to meet the staff or see the ward or unit before a planned hospital stay, you or a friend or family member can telephone and ask if this can be arranged. It may be helpful to write down anything you would like to ask (or request someone does this for you) and bring this with you during any arranged visit.

- Staff may not always be aware that you have dementia but when you come into hospital they will ask some questions about you. Telling staff that you have dementia, and what areas you have difficulty with, will enable them to better meet your specific needs
- All staff have access to a National Dementia training programme. There are also staff who have specialist training in dementia care e.g. Dementia Champions and Alzheimer Scotland Dementia Nurse Consultants who can help to provide any additional help and advice
- A personal plan of care suited to your individual needs should be developed in partnership with you
- Your Getting to Know Me document can also help inform your plan of care and enable staff to understand your likes and dislikes, your normal routines, what may be upsetting for you and how staff can help to make you feel at ease
- Staff will also work with you to ensure the right plan is in place for you, in preparation for your return home. On the day of discharge, they will arrange for you to go home in the daytime rather than in the evening.

It is very important that you feel safe when you are in hospital. Staff will try to make your hospital stay as comfortable as possible but if you are worried about anything please let someone know.

5

What should I do if I have any concerns about my care?

There are standards that support and drive quality care for people with dementia in general hospitals but if you have any concerns please:

- Speak to a member of staff as soon as possible about your concerns. If you do not feel comfortable doing this, ask a friend or relative if they can help or ask to be put in touch with advocacy services
- Every hospital has a patient feedback system which you can use to let people know what was good about your stay or if anything was not so good and how you think things can be made better.

We hope your hospital stay is a smooth and comfortable as possible.



For more useful information like this, please keep up to date with our website: www.alzscot.org



How Self-Directed Support worked for us

By Michael Turnbull, Carer



In 2012, my wife Mary was diagnosed with frontotemporal lobe dementia and aphasia, aged 73. At first Mary saw a psychiatrist three times a year and had input from both a Community Psychiatric Nurse and Speech and Language Therapist. However, once these medical interventions had run their course, Mary was discharged.

Mary tried day care but it didn't suit her needs. The way she communicated this was interpreted as aggressive behaviour and led to her not being allowed to go back. Similarly,

Mary had a difficult time getting used to the home care staff. Unfortunately, the care agency then withdrew their services for a week without explanation.

Discharged from medical care and important social networks, it felt like opening a door onto a featureless landscape where there were no road signs, without a map.

I began to look in to other ways to help care for Mary and came across Self Directed Support (SDS) in 2014 from a carers organisation. One of their staff met me at home with a care broker from the local authority. Mary's needs fitted into the 'critical' category of their criteria. The care broker said Mary's personal care would

be funded however important social opportunities, like going to the gym or the pool, wouldn't be funded.

We chose Option 1 of SDS which put me, as Mary's Power of Attorney, in the position of managing her direct payments. I approached Lothian Centre for Inclusive Living (LCIL), an organisation that supports people who use SDS to help me advertise for a number of Personal Assistants to supplement the staff who would continue to support Mary with her personal care. They also helped me by calculating

balance sheets, generating pay slips and dealing with HMRC.

The first Personal Assistant (PA) started supporting Mary two years ago. Each PA who works with Mary has a unique set of skills and abilities, and they have all worked together to provide her

with the consistent, yet flexible, support she needs. Most importantly is the benefit the PAs have been to Mary. She has built a relationship with them and can trust them, and they understand how to communicate with her. The PAs enable Mary to do the things she enjoyed before she was diagnosed with dementia, such as going to the gym, swimming and art. Mary created some incredible abstract

pictures that appeared to reflect her understanding of dementia – they're going to be exhibited later this year. She now goes to a number of day centres and enjoys the variety of people she gets to meet. In between times we all suggest places we think Mary would like to go – and the PAs know her well enough to read her feelings about what they're doing, even if she's not always able to verbalise her choices.

Alzheimer Scotland, through their local Dementia Advisor and National Self Directed Support Manager have offered guidance at many stages of our journey. In 2018, they provided bespoke training to Mary's PAs. A person who understands more about dementia can see various reasons why a person might be acting or feeling a particular way; and they have an awareness of various options to support the person accordingly. The PAs are now even more responsive to Mary's needs.

When you manage your direct payments, your situation should be reviewed annually. In our case no one from the local authority had seen Mary since the original assessment in 2014. As a result we were paying a significant amount of money to supplement the allocated budget. I contacted the Minority Ethnic Carers of People Project (MECOPP), an organisation which specialise in legal support for carers and families. Their 3 R's Project provides advice and information on

legal rights under SDS, human rights and equalities legislation. Following their intervention Mary's care needs have been reviewed, her direct payments have increased, and her PAs continue to provide the support that has made such a difference to Mary's quality of life and her experience of dementia.

Although choosing Option 1 requires patience and a lot of resilience I would definitely recommend direct payments. Ultimately it has enabled me to personalise Mary's support and I can see day-to-day how much happier she is. I can understand why people might be reluctant to challenge the support they are offered, or try something new. They don't want to make their private life public; it can also be complicated and time-consuming; but in my experience it improved our situation. Not only did it make the review possible and increased the amount of money Mary receives but it lets local authorities hear the voices of people using the structures they have in place, so they can continue to develop them to work for everyone.

If you would like to hear more about Self-Directed Support, please visit: www.alzscot.org/SDS or speak with your local Dementia Advisor.



Online Surgeries

If you're interested in finding out more about the support that's available for people living with dementia, carers and families, log in to one of our online surgeries and speak to a member of staff. You just need internet access, Google Chrome and a laptop, smartphone or tablet.

Joining instructions:

Type the link below into your Chrome browser and ensure your camera, microphone, and speakers are on and working.

www.alzscot.org/online-support - then click on the surgery you wish to join.

This will enter you into a Tech Surgeries Waiting Area and from here a member of our Tech Team will invite you onto a call with a member of our staff.

If the Tech Team are on another call, they will call you as soon as they are finished.

If you are not able to get on to the online surgery, if you still have questions or just need to talk to someone you can contact our freephone dementia helpline on 0808 808 3000.

Self-Directed Support

11am-12pm

- 22 May 2019
- 17 June 2019
- 24 July 2019
- 26 August 2019
- 25 September 2019
- 29 October 2019
- 27 November 2019
- 16 December 2019

Dementia Advisor

10am-11am

- 7 May 2019
- 4 June 2019
- 2 July 2019
- 6 August 2019
- 3 September 2019
- 1 October 2019

Occupational Therapy

10am-11am

- 2 May 2019
- 6 June 2019
- 4 July 2019
- 1 August 2019
- 3 September 2019
- 1 October 2019

Confident conversations – 'getting out and about'

By Charlotte Swarbrick, National Digital Lead, Alzheimer Scotland



We get asked a lot about Global Positioning System (GPS) type devices by people living with dementia and their carers. GPS trackers help to track the location of a person remotely and can be beneficial for a person with dementia to have to help them remain independent. These trackers will not suit everyone's needs and the decision to have one requires consideration of the person with dementia's own needs and wishes. GPS can be found on certain phones and watches. There are also specialised GPS products which attach to keys and go around your neck. Each GPS device varies in what it can provide and it's important to consider the quality of the map

platform, its signal, battery life and how many people can access the tracker. Also, for a tracker that isn't on a phone or watch, it may be important to consider how the tracker can be worn in a manner that's subtle or looks like a fashion accessory.

There is no product that suits every single person's needs and it's for that reason that we don't recommend one specific product. Whatever products you end up with should be person focussed, taking into account the person using the device and working alongside an overall plan of support.

For more information on GPS trackers and other products visit www.dementiacircle.org or discuss with your local Dementia Advisor

Purple Alert community helps in search

By Tommy Petillo, Purple Alert Coordinator, Alzheimer Scotland

Purple Alert is the first app of its kind in the UK which helps to find people with dementia when they are lost. Audrey and James* were the first family to benefit from Purple Alert, which we hope will continue to help people with dementia and their families for many years to come.

Since her diagnosis of dementia Audrey's husband James has been her main carer, with support from their son Ian who lives locally. James ended up in hospital last year, meaning Ian had to think of alternative solutions to ensure his mum was still supported.

These included leaving her reminders to stay safe and not leave home however on the day of his hospitalisation, James had routine medication delivered to their house, causing Audrey to attempt to deliver this to James in hospital. As Ian was unaware of his mum's whereabouts and was unable to get in touch with her, he then contacted the police on 999 and his dad who had previously created a profile for Audrey on Purple Alert, which included a photo. James then created an alert on the app which was sent to everyone who had downloaded Purple Alert in a 30 mile radius of Audrey's home address.

Fortunately one of the people who received the alert was Lesley, who was out walking when she

1 friend

1 colleague

1 family member

1 App



received the notification. Upon looking at Audrey's profile photo, she realised that she was sitting in a bus stop a few metres away from her and managed to reunite Audrey with her family.

Audrey had been missing for approximately four hours when Lesley found her. This was the first time Purple Alert was pivotal in finding a missing person but really demonstrates its importance in keeping people with dementia safe and the need for as many people as possible to download the app, to ensure a large online community is accessible to everyone.

You can download Purple Alert on Google

Play (Android) or the App Store (Apple)

**the names in this article have been anonymised*

Scotland's Dementia Awareness Week 2019

By Beccy Jardine, Campaigns and Social Media Manager, Alzheimer Scotland

Every June, people across Scotland come together to show their support to people living with dementia, through Dementia Awareness Week.

Those seven days in June make a big impact – it's our annual opportunity to break down the stigma of a dementia diagnosis, raise awareness of the support and care available, as well as dispel common myths.

This year Dementia Awareness Week will take place from Monday 3 to Sunday 9 June and focuses on two key areas:

Dementia research

The advances that research makes possible is astounding. Thanks to the latest studies, we are learning more than ever. Not just about dementia as an illness and what is most important when it comes to care and support and quality of life, but also what can be done to help prevent dementia.

We're also looking to the future. We work closely with our partner organisations in Scotland but also across the globe, to ensure breakthroughs in care and treatments take place, in our quest to ultimately

finding a cure. It's only with action today, that we can enable the steps of progress for years to come in Scotland.

Dementia research is crucial to making a difference for people living with dementia now, and in the future. Did you know that dementia research relies on volunteers who do not have dementia, as well as those who do? During Dementia Awareness Week, we'll be encouraging people across the country to sign up to take part in dementia research.

Local care and support

Making sure people living with dementia have access to the right care, information and support is at the heart of everything we do at Alzheimer Scotland. We provide a wide range of dementia-specific support in local communities across Scotland. Dementia Awareness Week is a great time to get the word out about the help which is available to people living with dementia, so we'll be reaching out across all areas of Scotland.



DEMENTIA AWARENESS WEEK 3-9 June

How to get involved

We would love for you to be a part of Dementia Awareness Week 2019 – we can only make the week a big success with your help. There are lots of ways to get involved:

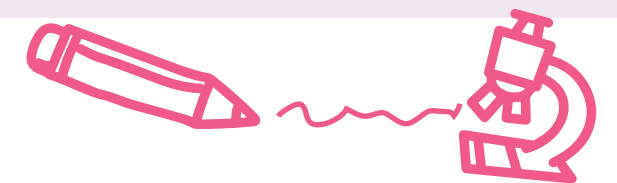
Order an awareness pack to learn more about dementia and dementia research

Help us spread the word about dementia and dementia research by ordering one of our awareness packs. It includes lots of helpful information on dementia research, along with information on the support and services Alzheimer Scotland provides.



Sign up to take part in dementia research

Pledging to participate in dementia research is quick and simple with our partners; Join Dementia Research. Signing up is the best way to keep up to date with new research projects and trials that you might be eligible for.



Get involved on social media

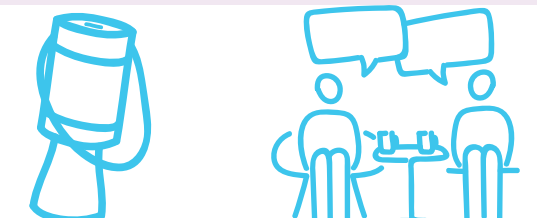
Throughout Dementia Awareness Week we will be posting information on dementia care, support and research across our social media channels. We will also be starting conversations about dementia and asking for your experiences. You can get involved by commenting, liking or sharing our posts. You can also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



@alzscot
@AlzheimerScotland
@alzscot

Hold your own fundraising event

Holding a fundraiser in support of people living with dementia and Alzheimer Scotland is the perfect way to be a part of Dementia Awareness Week. Our Fundraising Team can support you from the planning stage, right up until your event and give you great ideas for fundraising events.



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

Annual Conference

By Kim Kilgour, Event Manager, Alzheimer Scotland



Join us at our annual conference which takes place at the start of Dementia Awareness Week. We will delve into the advances of current dementia research, as well as exploring the innovative support available to deliver better care for people living with dementia today. For the first time ever, the conference is offering practical workshops that have been specifically tailored for people living with dementia and carers which will provide take-home advice and ideas, as well as an opportunity to attend one of our new one-to-one clinics to discuss what matters to you. The day will feature panel discussions and presentations that will investigate the key aspects of risk reduction, why dementia care should be free and ask pertinent questions of the Government about Scotland's commitment to dementia research.

You'll have the opportunity to learn more about the pioneering improvements in specialist dementia care and acute care and hear about the outcomes of innovative dementia research projects in the ongoing quest to find a cure. We'll hear from prominent dementia researchers including Professor Craig Ritchie (Chair of the Psychiatry of Ageing and Director of the Centre for Dementia Prevention at the University of Edinburgh) and Dr Tom Russ (Co-Director of the Alzheimer Scotland Dementia Research Centre), along with experts from Alzheimer's Research UK, the National Institute for Health Research and the Centre for Policy and Practice at the University of the West of Scotland. With a choice of four breakout sessions and four practical workshops, you'll have the flexibility to tailor the day to suit your specific interests:

| Breakout Presentations | Practical Workshops |
|---|---|
| Prevent now: Brain health and dementia research | Get creative: Try out therapeutic activities that help to support the symptoms of dementia; such as music and art therapy |
| Care today: Improvements and innovations in specialist dementia care | Living well: A selection of information stations offering practical tips. Topics may include safety around the home, effective communication and healthy living. |
| Care today: Forging ahead in acute care | Products & technology: Discover a wide range of different products and technology which are specifically designed to support the independence of people with dementia |
| Cure tomorrow: Research developments | Being good to yourself: Try out a practical sessions, such as mindfulness, yoga or aromatherapy |



Prevent now • Care today • Cure tomorrow

Monday 3 June 2019, EICC, Edinburgh



“ The vast knowledge and information disseminated to me proved empowering and inspired me to help spread the word about dementia. I picked up valuable tips about how I might deal more positively in interactions with the family member whom I care for. The conference has given me the confidence to carry on and focus on the positives and see the needs and capabilities of the person rather than just the diagnosis of dementia in front of me. ”

Our bustling exhibition area will showcase everything from product demonstrations to poster-board presentations and videos. Please view the website for a list of this year's exhibitors. 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 financial, legal, property and technology sectors. You won't want to miss out on what is sure to be the most thought-provoking conference for Scotland's dementia community. You'll leave inspired with new information, support and ideas that will help us all in our ambition to prevent now, care today, cure tomorrow.

Early Bird Discount

£95 early bird members' rate available until 26 April. Free tickets available for people living with dementia, their partners and family carers. **BOOK NOW!**

For more information, or to book your place, visit <https://events.alzscot.org/> or call 0141 410 0104.

Prevent now, Care today, Cure tomorrow

Alzheimer Scotland is continuing to campaign for the rights of people with dementia and carers, whilst providing high quality specialised dementia specific support. We are also committed, through our many partnerships, to investing in research that improves our practice, information provision and to ultimately find a cure to make sure nobody faces dementia alone.

Alzheimer Scotland believes high quality research drives forward improvements in providing excellent care. To support this, we were instrumental in the creation of Scottish Dementia Research Consortium (SDRC) in 2012 with the key objective to bring researchers from across Scotland with various skillsets (from clinical to social sciences) to collaborate and look at how to prevent, care for and cure the brain diseases that lead to dementia.

This is an innovative approach which has led to Scotland being viewed as a dynamic melting pot, attracting pioneering studies such as the PREVENT dementia research programme (p23) and the Scottish Government endorsed 'Being Home' report (p25). Over the next few pages, you will hear more from the researchers involved in SDRC demonstrating our successful partnerships within the research community.

To find out more about the aims of the SDRC, visit www.sdrc.scot.

Prevent now – reducing your risk of dementia

By Kirsty Stewart, Head of Communications and Events, Alzheimer Scotland

Our recent Winter Lecture held at the Old Fruitmarket in Glasgow saw Prof. Karen Ritchie take to the stage to deliver a presentation entitled 'Myths and Dreams.'

Prof. Ritchie told the audience that whilst many people with Alzheimer's and their carers have begun the 21st century with a common feeling that research has hit a brick wall, that research has come a long way since the 19th century when people with Alzheimer's were shut away as 'lunatics'. This recent period of disappointing drug and lifestyle intervention trials has actually allowed researchers to radically change their concept of Alzheimer's which has led towards new approaches to treatment.

Prof. Ritchie told us;

"Firstly, we no longer believe dementia to be an inevitable result of the ageing process. Amongst the oldest old around half do not have dementia, and many people who are found to have Alzheimer's at autopsy showed no sign of dementia up until their death. We also know that Alzheimer's is treatable. We cannot only simulate the disease in healthy animals but prevent and even reverse it. While mice are not humans, the fact remains that it is do-able.

Secondly, but perhaps the most important revolution in our thinking, is our understanding that dementia is not the beginning of the disease but rather the end stage. Alzheimer's is now seen as not a disease of the elderly but a clinically silent brain disorder which begins in middle age and which advances unchecked for decades until it finally starts to interfere with memory and other cognitive functions. Therefore researchers are

now focusing on brain changes in mid-life (persons in their 40's and 50's) and researchers are looking to find treatments that target the earlier stages of Alzheimer's. The message to young adults, especially those with a family history of the illness, is that what is good for the heart is good for the brain."

Prof. Karen Ritchie concluded her lecture by confirming, researchers will still continue to look for ways to slow down dementia once it starts. This may prove to be a more difficult, but not impossible, task. We have after all achieved this for the mouse and it was mice landing on the moon which later opened the way for our astronauts.



The PREVENT Dementia Research Programme

By Professor Craig Ritchie, Director of the Centre of Dementia Prevention, University of Edinburgh

We now know that Alzheimer's disease has a long 'silent period' where the underlying damage in the brain builds up gradually for many years, if not decades, before problems with memory or thinking become apparent.

However, given this silent period could begin 20 or more years before obvious symptoms emerge this raises some tricky questions:

1. What exactly do we measure to tell us someone is at risk of dementia?
2. What do we then measure to show us whether or not an intervention is working to reduce someone's risk?

What we need are reliable, measurable markers that show us early changes have begun to happen in the brain, even if we cannot directly see this impacting on someone's daily life. Much like measuring cholesterol and blood pressure can be used to warn of changes in cardiovascular health which may put someone at risk of future heart disease or stroke. The successful strategies for delaying or preventing dementia could look very similar, likely a combination of changes in lifestyle, social activity and for some people, a drug. Importantly, identifying these measurable markers of early disease will allow us to track whether a potential new therapy is working.

The PREVENT Dementia Research Programme is a UK and Ireland wide initiative led from the University of Edinburgh. The study will follow 700 volunteers between the ages of 40-59 over a number of years and use detailed thinking and memory assessments, clinical examinations, brain imaging and genetic analysis to track how the brain changes throughout midlife. The aim of PREVENT is to identify these important biological and psychological markers that will allow us to predict who is at greatest risk of dementia and ultimately help us develop strategies to intervene and prevent the disease taking hold.

"The concept of PREVENT aims to uncover the reasons for the development of dementia and thereby reduce and eventually remove the risk of being diagnosed with one of the fastest growing and devastating illness of our time. It is interesting to look at lifestyle changes that can be made to lower risk but also investigate how incidents and behaviours from birth and inherited genes may impact on risk levels. For me, PREVENT provides hope for the future and is something I am proud to have been involved with."

PREVENT Participant

To find out more about the PREVENT Dementia Research Programme, visit www.preventdementia.co.uk

A tweet a day from @AHPDementia

By Elaine Hunter, National Allied Health Professionals Consultant, Alzheimer Scotland

As Allied Health Professionals (AHP) we knew we had to find new ways of working that increase our visibility and engagement while also integrating our AHP dementia policy: Connecting People. Connecting Support (Alzheimer Scotland 2017), to local practice.

We decided twitter offered us a real opportunity to raise awareness of the work of Allied Health Professionals while also transforming the way we communicate with people living with dementia, their

families and supporters. Therefore, we took to twitter and began our daily tweets at @AHPDementia in January 2018.

One year on, we now have a group of experienced occupational therapists, podiatrists, physiotherapists, dietitians and speech and language therapists tweeting daily. The themes and images of the twitter content follow the AHP approach and outlined below are an example of some of our twitter posts.



Monday: Supporting families & carers as equal partners

Carers can help maintain the person they care for's psychological wellbeing by including the person with #dementia in activities of daily living. Encouraging the person to be as independent as possible will help to retain skills.



Tuesday: Enhancing daily living

Occupational therapists CAN enable people to continue to work after a diagnosis. They can suggest adjustments such as reducing background noise, flexibility with breaks, use of memory prompts and organising the desk with only the necessary tools required for the job.



Wednesday: Adapting everyday environments

Pictorial signs to identify what is inside drawers and cupboards in the kitchen and bedroom can aid a person with dementia's orientation and independence in activity. Style of the signage will depend on the person's strengths and needs.



Thursday: Maximising psychological wellbeing

Communication environments matter! Facing the person we're talking with helps conversations. Try finding a place and time to talk where there aren't a lot of distractions present. Repeat back words you hear to show that you're actively listening.

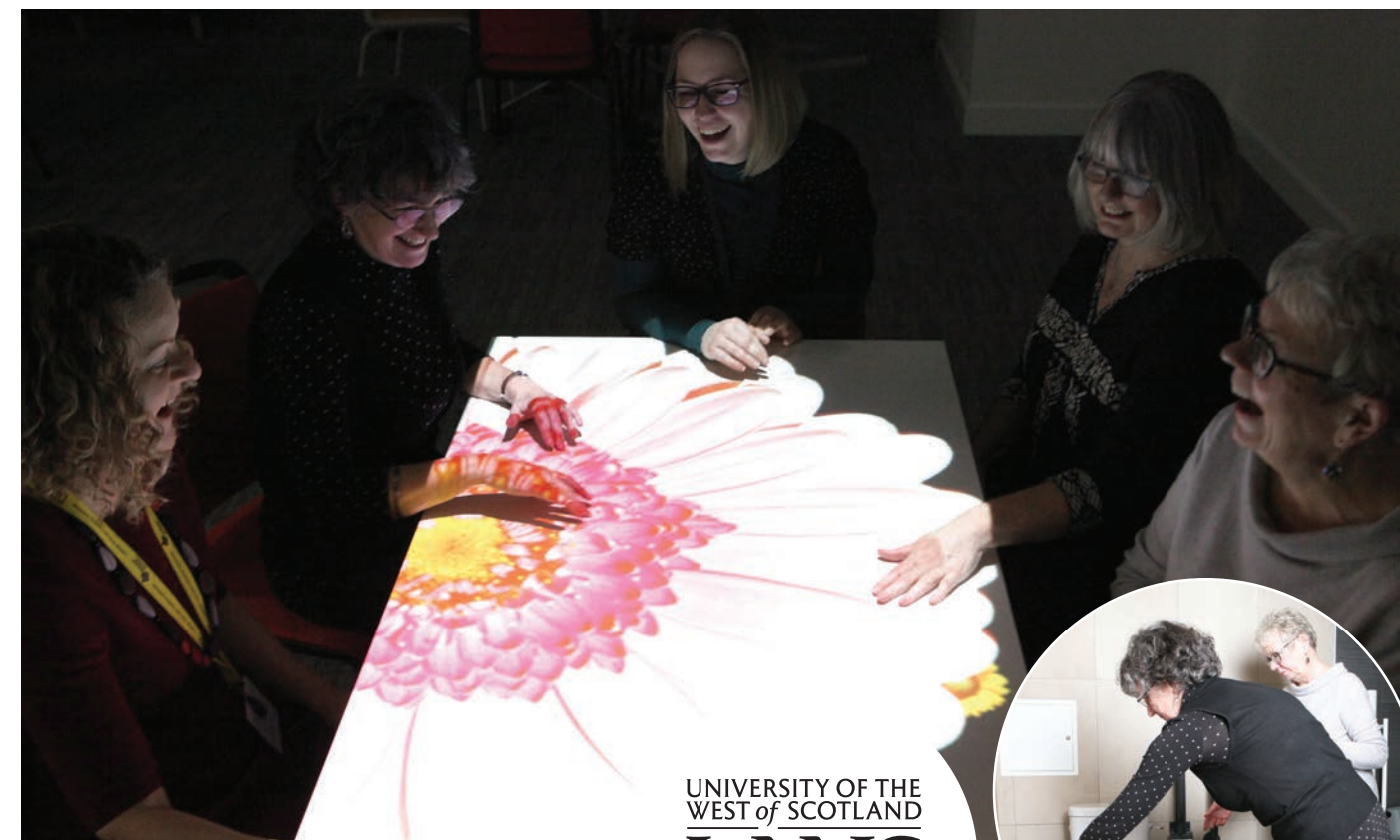


Friday: Maximising physical wellbeing

In our lifetime we will walk around 150,000 miles, that's more than four times round the earth. Walking is the nearest thing to 'perfect' exercise in terms of a safe, all-round workout and it doesn't cost a penny or need any special equipment.



Join the conversation – follow us on twitter @AHPDementia and #AHPConnectingPeople and share your own hints and tips, or retweet ours. If you don't use twitter then you can email Elaine Hunter: ehunter@alzscot.org



Care today

Dr Margaret Brown, Deputy Director,
Alzheimer Scotland Centre for Policy and Practice

Care is needed now and in the future, no matter what happens.

As highlighted earlier in this magazine, Alzheimer Scotland is committed to delivering high-quality specialised dementia support. We are continuously innovating and researching for improved care today for people with dementia and carers. In addition to providing this day-to-day support at the heart of local communities to ensure nobody faces dementia alone, Alzheimer Scotland has invested in The Alzheimer Scotland Centre for Policy and Practice, at the University of the West of Scotland (UWS), to continue to drive developments in real life, fundamental care initiatives and achievements, such as:

- Publishing and presenting to the Parliament, 'Being Home'; a report on housing for people with dementia in Scotland
- Focussing on dementia research which ranges from people still in work, to Palliare; a European research project examining care near the end of life
- Ensuring tomorrow's workforce is knowledgeable, skilled, confident and experienced by delivering an award-winning programme which facilitates repeat learnings and practice in the community, in people's homes, resource centres, care homes and a range of hospital settings over their three years with the university. The university campus even hosts a real-life replica of a hospital ward

and someone's home, so the students can build their confidence before putting their learnings into practice in the field. In addition, the third-year students visit primary schools and use the Centre's learning resource, 'Class in a Bag' to help children, as citizens of Scotland, understand people living with dementia

- Ensuring our workforce of today is suitably trained to support people with dementia and their carers, by developing and delivering the Scottish Government programme 'Dementia Champions' for acute care. The Centre is soon to have completed training for 1,000 champions (see p7). In addition, in the field of mental healthcare, the Centre has developed and provided the fundamentals of care programme to the Dementia Specialist Improvement Leads
- All of the Centre's training is based on a 'Care Empathia programme' which structures teachings on the head (learning), the heart (feeling) and the hand (practical skills). This lets students and professionals think again about how practical care is experienced by the person living with dementia. Practical application of learning makes it a very real and empowering experience.

For more information about the Alzheimer Scotland Centre for Policy and Practice, visit:
<https://research-portal.uws.ac.uk>

Fair Dementia Care

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



As well as providing good quality care, Alzheimer Scotland is invested in campaigning for equal rights for people with dementia, their families and carers.

As you may have read in the Winter 2018 edition of Dementia in Scotland, Alzheimer Scotland have been working with The Fair Dementia Care Commission to publish a report: Delivering Fair Dementia Care for People with Advanced Dementia. The report highlights that, despite the complex nature of advanced illness, the needs of people with advanced dementia are not recognised as healthcare needs. This results in two glaring inequalities faced by people with advanced dementia, their families and carers. People with advanced dementia do not currently have equality of access to the specialist healthcare they need on a par with other complex, progressive and terminal illnesses and because of this they face a disproportionate impact of social care charges. Chaired by Henry McLeish, the commission brings together a small group of experts to work in partnership with Alzheimer Scotland to define advanced dementia and to set out a compelling case to end these inequalities.

This report is the first step in Alzheimer Scotland's campaign to deliver free healthcare to those with advanced dementia. The report makes several recommendations to the Scottish Government, The Convention of Scottish Local Authorities (COSLA) and Integration Joint Boards aimed at ending these inequalities.

Key Findings

- Dementia is caused by progressive neurological disease processes, such as Alzheimer's disease
- Advanced dementia produces complex health and nursing care needs
- People with advanced dementia do not currently have equality of access to the healthcare they need – instead advanced dementia remains essentially a social care response
- People with advanced dementia are disproportionately subject to social care charges for what are primarily health and nursing care needs
- People with advanced dementia are paying an estimated £50.9m per year in social care charges for care which doesn't provide the health or nursing care they require
- The current system of social care charges is complex, lacks transparency and is variable across Scotland.

Recommendations

- That the Commission definition of advanced dementia is used and implemented in practice
- That advanced dementia is recognised as a continuum which includes, but is not confined to, end of life and dying
- That the Scottish Government commits to recognising that the needs of people with advanced dementia are healthcare needs and ensure equality of access to appropriate health and nursing care, which is free at the point of delivery
- That the Scottish Government commits to investigating the costs of implementing appropriate and free healthcare for those living, and dying, with advanced dementia
- That the Scottish Government, COSLA and Integration Joint Boards commit to ending the current lack of transparency, complexity and variability in current non-residential care charging provisions across Scotland
- That the recording of dementia (including advanced dementia) prevalence across all health and social care settings is urgently required to support better understanding of demand, allocation of resources and improved care and support
- That all local authorities and health and social care partnerships make local charging policies accessible and readily available.

An open letter to the Scottish Government

Alzheimer Scotland's commitment to ending the inequity of the lack of access to free healthcare in advanced dementia responds to, and is informed by, the lived experiences of families like that of Elaine Deehan. Elaine's family's experience is an all too familiar story of the impact of an unfair system which fails to recognise the healthcare needs of people with advanced dementia. Elaine's mother, like many other people, has not received the healthcare she needs when her illness became advanced. She has also faced the additional inequity of social care charges for care which does not meet her healthcare needs. Elaine has written the letter below urging the Scottish Government to accept the recommendations of Alzheimer Scotland's Delivering Fair Dementia Care for People with Advanced Dementia report.

"I am writing in the hope that my family's experience of advanced dementia will help you to understand the importance of Alzheimer Scotland's Fair Dementia Care report and to ask you to consider the recommendations they have presented, to make a fairer system for people with advanced dementia and their families. In particular, to acknowledge that people with advanced dementia are in need of healthcare which should be free at the point of delivery on an equal footing with others who have complex, progressive and terminal illnesses.

My mum Pat has been in the advanced stages of dementia since 2015. My family moved up from England to help care for her, however after three years of doing so her dementia progressed rapidly. Up until this point my mum had been going to a day-care centre and a nursing home for respite breaks as we had no other support, however these environments were finding my mum's needs more difficult to manage.

Our requirement for more help became evident when my brother-in-law died and I was unable to get any emergency carer support. My mum was taken into a residential home where she then remained for 10 months at a cost to her. In this 10 month period, she had to visit A&E 11 times because her care home couldn't meet her healthcare needs. On her last visit to hospital, she was admitted for three weeks due to a fractured skull however still had to cover the costs of her place at the care home. On top of this were the costs to the state for my mum's stay in hospital. If my mum had access to the free healthcare on an equal basis as those with other progressive illnesses she would've had a better quality of life which would have saved the numerous crisis interventions, which were not only costly in the stress placed on her and her family, but financially to her and to the health and social care system.

The emotional impact of being a carer and watching someone you love deteriorate is hard enough without the added worries of how they are going to pay for care. For three months in a nursing home alone, it has cost my mum £14,000. The current system is broken and unfair. The cost of care for my mum's healthcare needs could have been vastly reduced if there was better access to healthcare for her in the community.

I know our family are not alone in this experience. People with dementia are treated unfairly compared to people living with other illnesses. I am asking you to consider the recommendations of the Fair Dementia Care report and listen to the lived experiences of people with dementia, their families and carers to ensure a fairer system for people with advanced dementia.

Yours sincerely

Elaine Deehan

Alzheimer Scotland will be providing updates and asking for your support as we campaign for people with advanced dementia to have equal access to free healthcare just like other progressive illnesses in Scotland. To receive these updates and to support this campaign please sign up by visiting www.alzscot.org/fairdementiacare.

Cure tomorrow? Prevent today!



Alzheimer Scotland Dementia Research Centre

By Dr Tom Russ, Co-Director, Alzheimer Scotland Dementia Research Centre

The Alzheimer Scotland Dementia Research Centre at the University of Edinburgh is involved in a wide variety of areas of dementia research. One important project is the Dementia Brain Tissue Bank which is maintained by the Medical Research Council Brain Bank at the Royal Infirmary of Edinburgh. Anybody diagnosed with dementia who wishes to donate brain tissue after they die can sign up to the register. They are then visited by a member of staff from the Neuroprogressive and Dementia Network (which covers the whole of Scotland) who help them to fill out questionnaires and conduct cognitive tests. This brain tissue bank is a vital resource for research because the person's characteristics in life can be compared with their brain tissue. This is particularly important because we now understand that the brain changes which lead to many dementias, such as Alzheimer's disease, begin decades before symptoms appear. Indeed, many people with marked changes in their brains live to old age without ever developing any symptoms of dementia. One important way to understand the link between the symptoms in the person and the changes in the brain is by studying brain tissue such as that collected in our brain tissue bank.

Our Centre is also working with colleagues nationally and internationally on the effect air pollution has on

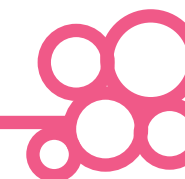
the risk of dementia, as there is a lot of attention on the effects of air pollution on health at the moment, with links to heart disease and stroke. It still remains unclear what the precise link is between air pollution and dementia; although we do know our environment is also related to dementia risk. This is another area where we hope to understand dementia more in order to help prevent it.

Much research today has the final aim of reducing an individual's risk of developing dementia. This could be achieved by individuals changing their lifestyles or – conceivably in the future – taking a dementia-specific treatment. A complementary approach to reducing dementia risk involves changes to the environment, such as the phasing out of diesel cars and the increased presence of 'low emission zones' in towns and cities. Thus, 'prevent today' means essentially the same thing as 'cure tomorrow' – more people living to old age possibly with dementia changes in their brain but no symptoms meaning fewer people developing dementia.

If you would like more information on the Alzheimer Scotland Dementia Research Centre, visit www.AlzScotDRC.ed.ac.uk or email AlzScotDRC@ed.ac.uk



Research leads the way



By Lindsay Kinnaird, Research Manager, Alzheimer Scotland

Research is the catalyst for change and holds the potential for advancements in the prevention, care and cure of dementia. It provides us with new developments in the support and treatment for people with dementia and their families today. It also holds the promise of preventing or delaying symptoms and even curing the underlying illnesses of dementia in the future.

Volunteers to take part in studies are an essential component of making research happen. Without them we would be unable to make the developments in our understanding. Our knowledge of dementia currently lags that of other major conditions, such as heart disease and cancer. We need more people to take part in studies.

Dementia research is interested in everyone and there is a wide range of different types of studies people can get involved in. This includes the clinical research studies that perhaps most would associate with research. But it is also about increasing our understanding of the social experience of people with dementia and their families with the aim of improving quality of life. There are also opportunities for people to get involved in informing and promoting research projects.

Join Dementia Research (JDR) connects researchers with people who want to take part in studies. It is a UK wide organisation that was developed by the National Institute of Health Research (NIHR) in partnership with Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society. Launched in 2015, it has now surpassed the milestone of over 11,000 people that have been matched up to take part in dementia research studies across the UK.

Registering with JDR is open to everyone over the age of 18. The research studies available are for people with a diagnosis of dementia, their family members, people with memory problems and those without a diagnosis of dementia or memory problems.

In registering with JDR, you will be asked to provide details about yourself that will help identify the studies that may be suitable for you to take part in. You can also express your interest in a study that you are matched to. Researchers can then contact you to provide more information and you can then decide if you want to take part. In joining JDR you have no obligation to take part in any study.

To find out more, visit the JDR website www.joindementiaresearch.nihr.ac.uk or contact Alzheimer Scotland Dementia Helpline 0808 808 3000.

A true experience of dementia research

By Dawn Ferguson, Content Manager, Alzheimer Scotland



When Anne Bowie signed up to a membership of a fortnightly magazine, she never dreamed that it would lead to her taking part in vital dementia research. Below, Anne shares with us her experience of taking part in a clinical trial.

"If you give cheerfully and you accept gratefully everyone is blessed. These are words that I read in a magazine recently, the same magazine that led me to sign up to dementia research and they fit in perfectly with how I feel about my involvement in research.

A couple of years ago I was reading my fortnightly edition of Yours magazine which has a real mix of stories that are relevant for my age group – I'm 77. There was an article about dementia research that was currently ongoing, and it just so happened to be taking place in Edinburgh which is not too far from me. I'm really interested in the research around life-limiting conditions; my daughter Pauline died age 45 of Multiple Sclerosis (MS) and, whilst it isn't the same condition, I knew then just how important research would be in to finding a cure for these conditions. I wasn't eligible to sign up for MS research but I've remained determined to play my part in making a difference for future generations. Also, my husband had Alzheimer's and died a few years ago so dementia research is something which is really important to me.

I decided to call the number on the article to sign up to Join Dementia Research (JDR). The people there connected me with the Neuroprogressive and Dementia Research Network which is a research department at the Western General Hospital in Edinburgh. I was invited in for an initial appointment where I had my DNA taken, which showed that a very small percentage of dementia runs in my family. I think it's so important to know this – why stick your

head in the sand? I, or other family members, may never develop dementia but it's worthwhile knowing that it's in our genetics. From the initial appointment, I was selected to take part in a two-year clinical trial which involves me going in monthly for an infusion, blood tests, MRI scans and different activities which are intended to test your brain. For example, at my most recent appointment I was given a selection of items and asked to name what they were. It's interesting to see how the results differ each month.

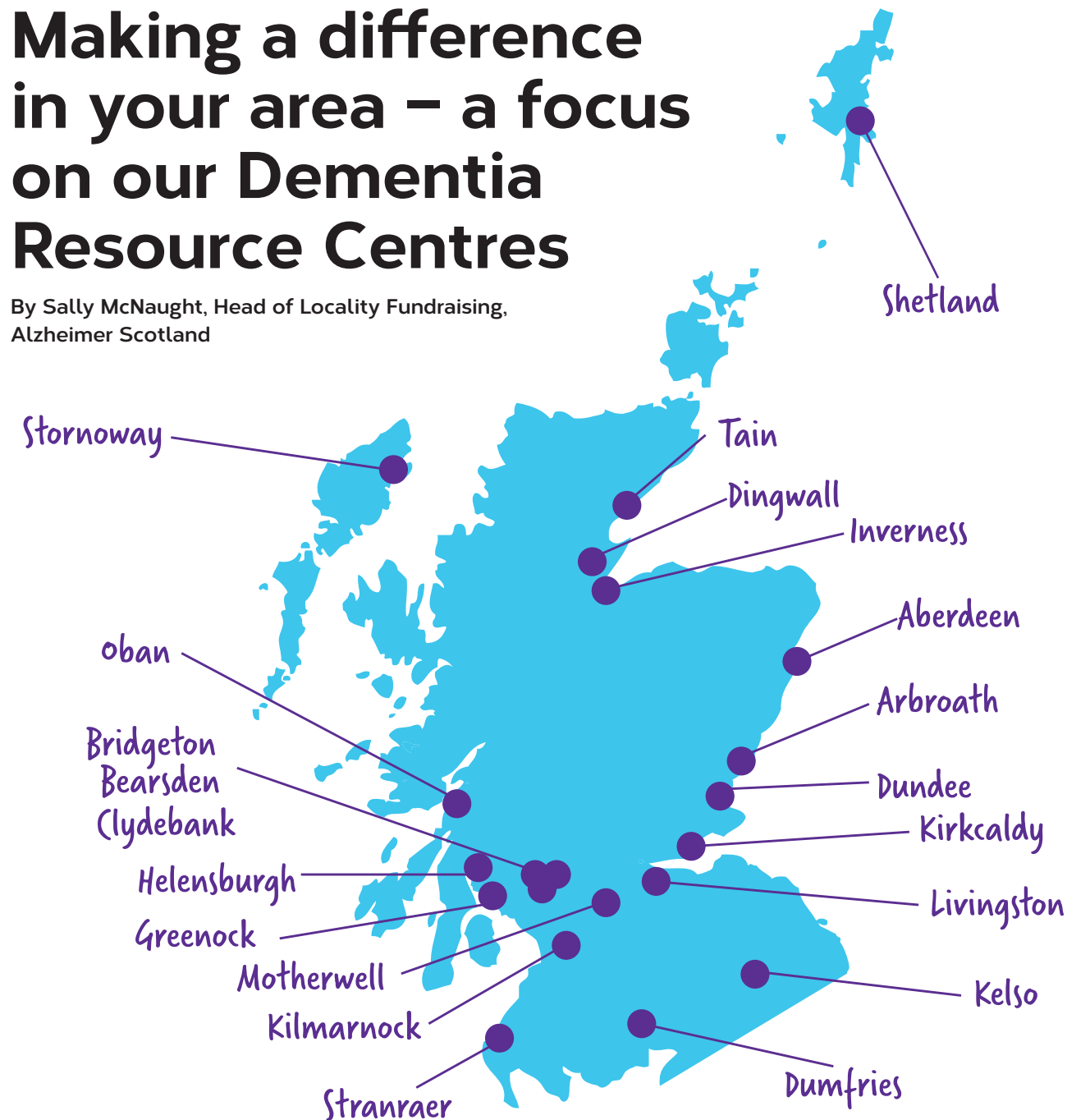
I can honestly say that I look forward to my monthly appointments. Prof. Craig Ritchie, who is leading the study, and his team at the Network and the Clinical Research Facility feel like extended family now; they look after me so well and we always have a bit of a laugh. It's as if they've been hand-picked based on how much they can put you at ease. There's nothing at all daunting about going there anymore, it's one of the highlights of my month.

My current clinical trial ends in August this year and I have been asked to take part in the extension, which will run for five years. I had no hesitation in agreeing to it. The thought that I could play a big part in finding a cure for dementia spurs me on, it feels so easy to agree to. I tell everyone I meet about my involvement in research and ask them to sign up too. It isn't scary, or daunting and you will gain so much in taking part. Even if it's just getting out once a month and meeting some extremely talented individuals, or the satisfaction of helping people in the future, I know you won't regret taking part."

If you're interested in taking part in dementia research, contact Phil Brown by email: Tay-UHB.ndntayside@nhs.net or by phone: 01382 423086.

Making a difference in your area – a focus on our Dementia Resource Centres

By Sally McNaught, Head of Locality Fundraising, Alzheimer Scotland



Alzheimer Scotland is proud of our work in local communities. 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. We are determined to do as much as possible to provide direct help and support for people with dementia and their families, whilst driving change at all levels of society and we simply cannot do this without fundraised income. Whether it's organising a coffee morning, taking part in a Memory Walk or setting up a regular direct debit your fundraising efforts are what helps us to make sure nobody faces dementia alone and it's important for us that you know how the money you raise or donate is spent. In this edition of Dementia in Scotland, we wanted to show you how your money has helped to build our portfolio of Dementia Resource Centres.

In 2009 there wasn't a single Dementia Resource Centre in Scotland. Now, just 10 years later, we have 21 across the country. These centres complement our wide range of other support which is available in local communities. Our Freephone dementia helpline is also available 24 hours a day, 365 days a year, for information and emotional support as and when it is needed, as well as other services in the communities where there isn't yet a Centre. Our aim is to make sure there is a Dementia Resource Centre in each locality and we are determined to achieve this but we can only do so with your continued support. We are so grateful to have your continued commitment to support over 90,000 people who are currently living with a diagnosis of dementia in Scotland.

To find your local available support, please visit www.alzscot.org or call our 24 hour Freephone Dementia Helpline on 0808 808 3000.

DM Hall raise thousands for charity

By Claire Du Preez, Corporate Partnerships Manager, Alzheimer Scotland



DM Hall, one of Scotland's largest independent firms of chartered surveyors, recently concluded a target-smashing two year partnership with Alzheimer Scotland and Macmillan Cancer Support.

Colleagues, partners and clients across the DM Hall network showed incredible enthusiasm and generosity during the charity partnership and threw themselves (sometimes quite literally) into their fundraising ventures. Working together, they delivered a fantastic two-year campaign, which raised a phenomenal £60,000 for Alzheimer Scotland and Macmillan Cancer Support.

On top of their spectacular 2018 Charity Summer Ball and successful Stand Comedy Nights, we also saw staff bungee-jump, run marathons, trek the Kiltwalk, take on Tough Mudder and hold countless bake sales, dress down days and raffles to reach this amazing total.

DM Hall Marketing Manager, Neil McKenzie, said: "We are very proud to have been involved in this partnership with two such deserving charities, helping to raise both funds and awareness. The results speak for themselves and we are thrilled to have raised such a significant amount, which we know will have a big impact for families across the country."

We're so thankful to DM Hall for supporting two fantastic charities.

We offer our corporate supporters a bespoke calendar of fun fundraising and awareness raising opportunities to engage, inspire and upskill workforces of all sizes. Could your company help support Alzheimer Scotland as our next corporate partner? For more information, email: cdupreez@alzscot.org.



Supporting the future of Stirling and Clackmannanshire

By Sally McNaught, Head of Locality Fundraising, Alzheimer Scotland



We would like to say a huge thank you to everyone who supported our Winter Campaign - 'What will you support?' Your help in this campaign ensures that we can continue our work in the heart of the local communities across Scotland and we're thankful for that. The Stirling and Clackmannanshire Branch have taken this message one step further and have committed to raising £100,000 towards funding a brand new Dementia Resource Centre in their area.

The committed team at the Branch have already got plans underway to hit their target including ceilidhs and afternoon teas. So far, they have been overwhelmed with support from the local community which includes businesses who all want to show their support. As well as fundraising, the hope is to raise vital awareness of dementia which will be done by holding Dementia Friends sessions. We are also exploring the potential of expanding some of our groups in to this area, such as walking netball.

It's going to be an exciting year of fundraising and we look forward to being part of something special.

If you would like to hear more about what support is available in your area, visit: www.alzscot.org

Supermarket support

By Karen Macdonald, Community Fundraiser, Alzheimer Scotland



Alzheimer Scotland Western Isles have been lucky enough to be chosen for their local Co-Op Community Fund for the third year in a row. The first year resulted in a £15,000 donation however the process for applying for the fund changed to allow local staff to choose the charities they would most like to support. Due to the relationships we had build in the first year, we were chosen again to benefit from this fantastic opportunity and we raised £22,491 in the second year. We've been extremely lucky to be chosen again this year and are looking forward to another excellent year working with the staff in store. Many of them have experience of dementia and we're lucky to be able to help support their local community.

Let us know if you are fundraising for Alzheimer Scotland. You can email: fundraising@alzscot.org.





Alzheimer Scotland has lots of fantastic ways to fundraise, however if you're looking for something that involves minimal effort and has no additional cost to yourself, then look no further.

Many companies nowadays are more aware of their responsibility to support charitable organisations. As an example, certain websites have introduced methods which allow shoppers to pick a charity of their choice which the company will donate to, at no extra cost to the shopper.

Amazon Smile is a new way to make a charity donation while you shop. Instead of visiting the normal amazon.co.uk website, customers can load up the special smile.amazon.co.uk address, select Alzheimer Scotland as their chosen charity, and shop as normal. The AmazonSmile Foundation will donate 0.5% of the price of all eligible purchases. You only need to

nominate your chosen charity the first time you use the site, and it will be retained for future use.

Savoo is a money-saving and online fundraising website with thousands of great discount codes and deals. You can now show your support for Alzheimer Scotland when you use Savoo Search, Save and Raise as your online shopping platform. (www.savoo.co.uk/charities). Your efforts cost you nothing because Savoo donates on your behalf. If you're looking to do some online shopping and want to get a great deal, Savoo has over 2000 vouchers and deals on at the one time which will help you save money and also support Alzheimer Scotland at the same time.

Help us spread the word with these two useful websites that let us all raise vital funds, whilst enjoying some retail therapy.

Making 2019 active

Here at Alzheimer Scotland, we are constantly impressed at the level of commitment shown by our supporters when it comes to setting themselves a challenge. From walks to treks, bungee jumps to cycles, you all show incredible courage and help us to make sure nobody faces dementia alone.

Do you think you've got what it takes to sign up to just two of the challenges on offer this year? Then read below!

The Kiltwalk

Do you have what it takes to don your tartan and walk for #TeamAlzScot? With a 23 mile Mighty Stride, 15 mile Big Stroll and 6 mile Wee Wander to choose from, there's a distance for all abilities. Join the thousands of other people walking for Scotland's charities and put your feet forward in helping us to support the 90,000 people in Scotland, living with dementia.

Glasgow - 28 April 2019

Aberdeen - 2 June 2019

Dundee - 18 August 2019

Edinburgh - 15 September 2019

To sign up, please visit www.thekiltwalk.co.uk, and don't forget to let us know so we can give you all of the support and much-deserved praise on the run up to the day!

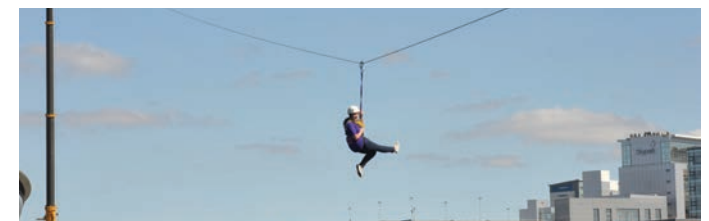


You can order your tartan here:
www.alzscot.org/tartan



Zipslide across the Clyde

What better way to fundraise for charity than to zipslide across the Clyde! It's perfect for thrill seekers who are looking for a new challenge and don't want to spend hours training. If sliding 1000ft from one side of the Clyde to the other doesn't get your adrenaline pumping, nothing will. We have various dates to be filled in 2019. This is a great challenge to do solo, or why not grab some friends, family or colleagues and make it a team day out?



For more information on both challenges, and for other ideas of how you can continue to support Alzheimer Scotland, please email: events@alzscot.org



**Alzheimer
Scotland**
Action on Dementia

DEMENTIA AWARENESS WEEK ³⁻⁹ June

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

Get involved

Find out more: www.alzscot.org/daw

#DementiaAwareness



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