

Dementia in Scotland



Summer 2014 – Issue 83





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Welcome!

Dementia Awareness Week is the biggest event in our annual calendar, and between 2 and 8 June our staff, services and volunteers organised a huge variety of events to raise awareness about dementia across Scotland. We are grateful to everyone who participated: your dedication and commitment is helping us achieve our goal of making sure nobody faces dementia alone. You can read about many aspects of Dementia Awareness Week on the following pages, including our annual conference, which focused on innovation, research and technology in dementia.

One of the highlights of the week was the very first event to take place. Called Voices of the Commonwealth (see page 6), this was pulled together by a small group of tireless volunteers who like so many others throughout Scotland give so much of their time, knowledge and skill to support our work.

During the week our Helpline Volunteers celebrated 25 years of providing an essential lifeline to people living with dementia and their carers. It is the effort and dedication of all our volunteers, supporters and members that gives us the added strength and force to ensure we continue to improve the lives of people with dementia and I want to thank you so much for

supporting all our staff and services committed to this cause.

And now we seek to further harness the spirit of friendship, compassion and commitment through our new Dementia Friends programme: not an entirely new initiative, but one that has been developed by our partners the Alzheimer's Society. We launched the Scottish version during Dementia Awareness Week and we have high hopes that we can use this to help bring an end to the isolation that can often come with dementia and further make sure no one faces dementia alone.

Elsewhere in this edition you'll also find a report on our new Kilmarnock Dementia Resource Centre, the latest addition to our network of centres on high streets across Scotland. This is already establishing itself as a hub to provide support and raise awareness about dementia. We have also included a feature on some of the important research work we are funding.



Henry Simmons
Chief Executive
Alzheimer Scotland



Quilts on display at the Dementia Awareness Week event at Duthie Park, page 16

24 HOUR
Dementia
Helpline
Alzheimer Scotland
Action on Dementia

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Feathered fundraisers



An East Renfrewshire family have come up with a novel way of supporting Alzheimer Scotland: by selling the eggs from the hens they keep in their garden. The idea struck Ron and Lisa Culley after they bought six hens a few years ago. Ron explained: 'We got the hens because we thought it would be nice for the kids – not to mention the fresh eggs every day.' However, with six hens laying regularly, they were soon left with a surplus. They came up with the idea of selling the eggs at work, with the money raised going to Alzheimer Scotland.

Ron, who works for the local government body COSLA, is very familiar with the work of Alzheimer Scotland: 'It's a brilliant organisation – full of energy and ideas but with a very strong social mission at its heart. Although we know the sums we've raised are very small, every penny counts. And we hope that by telling our story, others will think of quirky ways to raise money. We also like to think the hens are pleased with the social purpose they've acquired – almost every egg laid

supports someone with dementia.'

Lisa also has connections with Alzheimer Scotland: she works as a clinical psychologist specialising in dementia care and has recently joined NHS Education for Scotland. Her new role involves developing and delivering dementia resources and training for health and social care staff: 'It's something that's very important to me personally and professionally. Psychology has a huge role to play in supporting people with dementia and carers.'

Lisa was also keen to ensure that their two children, Arran (5) and Eilidh (2) had an appreciation of working for others. And besides, they have great fun with the hens: 'Eilidh delights herself by chasing them round the garden making chicken noises. Arran helps his dad with the maintenance – feeding them corn and cleaning their coop.'

Report criticises continuing care for people with dementia

On 2 June, the Mental Welfare Commission for Scotland (MWC) published a report called *Dignity and respect: dementia continuing care visits*. This described visits made by the MWC to 52 NHS units in Scotland that provide longer-term care for people with dementia. The inspectors found that a large proportion of the units were not providing appropriate care for people with dementia: 'Some units provided excellent care which respected the rights and dignity of people with dementia. However, the care and/or environment in too many units is failing to meet acceptable standards.'

The Scottish Government is drawing up an action plan in response to the report: you can read more in the next edition of *Dementia in Scotland*.

[Read the report](#)

www.mwscot.org.uk



Dementia Friends Scotland

People with dementia sometimes need a helping hand to go about their daily lives and feel included in their local community. Dementia Friends Scotland was officially launched at this year's Dementia Awareness Week conference in Glasgow on Friday 6 June. The project gives people an understanding of dementia and the small things they can do that can make a difference to people living with the illness – from helping someone find the right bus to spreading the word about dementia. The Dementia Friends scheme has already been hugely successful in England and will now be funded in Scotland by Alzheimer Scotland.

At the launch event, following introductions from Henry Rankin and Caroline Brown, the Musical Minds choir led an audience of 400 people in a rousing rendition of The Beatles classic 'With a little help from my friends'. It was a wonderful, celebratory way to launch the scheme and we are hoping that many people will want to sign up.

If you would like to find out more about how to get involved, or how your workplace or group can take part in creating a dementia friendly community, visit the Dementia Friends Scotland website.



Picture: clark@clarkjamesdigital.com

www.scottishdementiafriends.org



On 3 April the Black Isle Dementia Café celebrated its first birthday with a soup and sandwich lunch at its new venue in Avoch. The café was set up following a public meeting called by the late Billy Barclay, which helped raise awareness of the needs of people with dementia on the Black Isle. Joining in at the anniversary event were local councillors and invited guests from the local community who congratulated the group on the difference it is making.

Alzheimer
Scotland
Football memories
sports dinner



**Friday 3 October,
Hampden Park,
Scotland's
National Stadium**

For further information
and booking please
contact Sheila Connell
at sconnell@alzscot.org
or call 0141 410 1062



Voices of the Commonwealth raise the roof

Dementia Awareness Week got off to a flying start on 1 June with a spectacular event at Glasgow Royal Concert Hall called Voices of the Commonwealth. During the concert, a 200-strong massed Scottish choir performed alongside nearly 100 choristers and choirs from across the Commonwealth. The gala evening was introduced by Jamie MacDougall, presenter of BBC Radio Scotland's Classics Unwrapped, who also sang with the Swingcats during the concert.

The night included performances by conductor and musician Gordon Cree and his wife, opera star Cheryl Forbes, as well as Jai McDowall, who won Britain's Got Talent in 2011. Music was provided by the Swingcats, Greater Glasgow Police Scotland Pipe Band and the Kirkintilloch Band. The choir accompanist was Anna Mavromatidi.

The concert was the brainchild of William Barr, who conducts two local male voice choirs. He explains: 'It began as an idea a couple of years ago and was something I thought we could link

with the Commonwealth Games. I discussed it with some friends and we decided to go for it. Booking somewhere as big as the Glasgow Royal Concert Hall was quite a leap of faith, but the support we had was magnificent.

I've previously raised funds for Alzheimer Scotland's Lanarkshire branch as my wife had dementia, and during her illness they gave me so much help that I wanted to give something back. A committee of four of us organised Voices of the Commonwealth: Rachel Laming, Angus Simpson, Jim Milligan and myself.

Initially there were up to 600 choristers interested in participating – including 200 from Commonwealth countries – and there wouldn't have been room for them all on stage! Not everyone could make it in the end, but despite that the stage was packed. We're still finalising the takings but we're confident the night raised over £8,000 for Alzheimer Scotland.



Booking the Glasgow Royal Concert Hall was quite a leap of faith, but the support we had was magnificent.

Learn new skills with Alzheimer Scotland



Alzheimer Scotland offers a range of accredited, modular and bespoke training courses that could be essential to you or your organisation's dementia practice and development.

Training courses are delivered to all sectors and industries, throughout Scotland, who are interested in raising their awareness and knowledge of the dementia field and its associated topics.

All courses are aligned to the Promoting Excellence Framework and incorporate the principles outlined in the Standards of Care for Dementia in Scotland and the national Dementia Strategy.

To find out more about the courses that Alzheimer Scotland offers, along with dates, times and venues of courses that are currently organised, visit www.alzscot.org/training





Picture: clark@clarkjamesdigital.com

Wonderful new resource centre opens in Kilmarnock

On 28 May our newest dementia resource centre opened in Kilmarnock – just in time for Dementia Awareness Week. The ribbon was cut by Jim Todd, Provost of East Ayrshire Council. The nationwide network of dementia resource centres is helping ensure that people affected by dementia can get information and support on their local high streets. People living in Kilmarnock and East Ayrshire will now be able

of help from Alzheimer Scotland as a carer, and I hope this resource centre will help many more people discover the support they are able to offer for people living with dementia.'

Our local dementia advisor will be based in the centre at 8-12 College Wynd, along with volunteer supporters such as Elspeth. The additional space it provides will mean staff can also develop more support groups. The building's interior is particularly special, having been designed by Graven, a world-renowned interior design company.

Joyce Gray, Alzheimer Scotland's Deputy Director of Development, worked closely on the project with Graven. She explained: 'It was an amazing experience working with such a talented design team. We worked in partnership to share our knowledge and create something really great. We will evaluate the space over the coming months by asking the people who use it how it works for them. We'll use their feedback to make any adjustments that can make it even better. Graven donated some of their design time for free but didn't compromise on the quality of the project. It is definitely a Graven building and we're hugely grateful to them.'

Henry Simmons described the new centre as 'a wonderful, welcoming space for people living with dementia'. During the opening ceremony, guests sang along with the Musical Minds choir, whose members performed renditions of classic songs including 'Bring me sunshine' and 'Consider yourself'. The choir – for people with dementia, their carers and supporters – is one of the community groups that will have a new home at the resource centre in College Wynd.



Picture: clark@clarkjamesdigital.com

to call into this welcoming building if they have a question or need advice.

During the opening ceremony, Elspeth Wallace, a volunteer befriender, talked about the importance of the new resource centre. Elspeth cared for her husband Ken, who lived with dementia for six years. She explained: 'I got a lot

Bairns host Football Memories League match

Scotland's first Football Memories League match took place on Saturday 3 May when Falkirk Bairns played Alloa at Westfield Stadium. The event was held in partnership with Alzheimer Scotland to help raise awareness of dementia, as well as boosting funds for the Football Memories League.

Alzheimer Scotland's Football Memories project trains volunteers to spend time with people with dementia who have an interest in football. Dozens of groups now exist across Scotland where fans meet to talk about teams and matches from the past, using images and memorabilia to stimulate memories. The hugely successful project is a partnership between Alzheimer Scotland and the Scottish Football Museum.

Saturday 3 May saw a new phase in this exciting project when the first ever 'Memories League Match' was held. During the match, Bairns fans wore a range of old Falkirk strips as they recalled club-related memories such as their first visit to Brockville, their first Falkirk top and their favourite player. During the

warm-up, Falkirk players wore Alzheimer Scotland t-shirts.

At half time several former players were introduced to the crowd and there was a can collection on behalf of the Alzheimer Scotland Football Memories League. Memories from former players, managers and spectators were recorded by staff from the Scottish Football Museum at Hampden Park for use in future sessions.

The success of the Falkirk vs Alloa match was followed up by Dunfermline against Cowdenbeath on Sunday 18 May. Other clubs, including Greenock Morton, have also expressed interest in supporting the league.

The Football Memories League has over 80 'teams', each supported by a trained football memories volunteer.

More info

www.footballmemories.org.uk



Far left: Falkirk player David McCracken. Left: Alzheimer Scotland Deputy Director Jim Pearson with Falkirk Chairman Martin Ritchie. Right: Falkirk players Stephen Kingsley and Luke Leahy.



PUERTO RICO

Carers Action Network takes its message to Puerto Rico

Alzheimer Scotland was recently strongly represented at the 29th global Alzheimer's Disease International conference in Puerto Rico. Jeanette Maitland, of the National Dementia Carers Action Network (NDCAN), gave a presentation entitled 'Getting to the heart of the matter: a personal journey towards making carers' voices heard'.

NDCAN is a campaigning and awareness-raising group whose members all have experience of caring for someone with dementia. The network is based on the principle that carers have a vital role to play in shaping health and care services, as well as unique knowledge of the person they are caring for, and a right to be listened to by professionals.

The group also presented a poster at the conference describing their impact in influencing public policy.

The international dementia community also heard from Janice Caine, Alzheimer Scotland Service Manager from North Aberdeenshire, who



Left to right: Lorna Walker, vice chair of NDCAN, Jeanette Maitland, Shridhar Lamichhane, Vice Chair of the Nepalese Alzheimer Society, and Amy Dalrymple at the ADI conference.

presented her recent research into using music to help support people with dementia under the title 'Is music the best medicine?'

Jeanette and Janice travelled to Puerto Rico with Amy Dalrymple, Alzheimer Scotland's Head of Policy. They also presented a poster about their work describing how it links in with Scotland's dementia strategies.

Alzheimer Europe Conference, Glasgow, 20-22 October 2014

Are you eligible for a Life Changes Trust award?

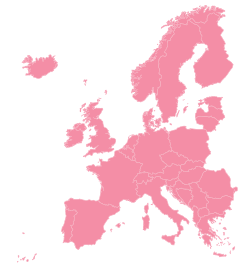
The Life Changes Trust is offering awards (bursaries) of up to £500 per person to facilitate attendance at this year's Alzheimer Europe Conference in Glasgow. The bursaries are open to people with dementia to attend the conference, along with either a carer or supporter. The awards can be used to cover registration fees, accommodation, travel and transport costs, meals and associated costs.

You can read more about the conference by visiting www.alzscot.org/europe

We expect these awards to be very popular and there are a limited number of supported places so early application is recommended. For more information and to apply, visit: www.alzscot.org/europe_bursary



European award for dementia friendly Motherwell



The innovative work that led to Motherwell becoming Scotland's first Dementia Friendly Town in 2012 was recently recognised with a prestigious European award. Arlene Crockett, Alzheimer Scotland's deputy regional manager for Glasgow, East Dunbartonshire and Lanarkshire, collected the award from the European Foundations' Initiative on Dementia (EFID) in Brussels on 24 March. She accepted it jointly with Paul Callaghan from North Lanarkshire Council, along with a prize of 10,000 Euros to contribute to the project.

The theme of the EFID awards was 'Living well with dementia in the community'. The judges chose projects that promote the integration and support of people with dementia and their carers in their local community. During the award ceremony there was musical accompaniment from the Foton Choir, made up of people with dementia, family members and volunteers.

Motherwell's winning application was made on behalf of the 'Dementia is Everyone's Business' project run by the North Lanarkshire Partnership. This has seen shops, services and businesses

signing up to learn about dementia and how they can take simple, practical steps to support people with the illness. Arlene explained: 'We've always been confident this initiative has had person-centred dementia care and support at its very core. This recognition only bolsters our resolve to continue to build on the work in place.' The North Lanarkshire Partnership brings together NHS Lanarkshire and North Lanarkshire Council with third sector organisations like Alzheimer Scotland, plus local businesses. It was one of a range of projects undertaken in North Lanarkshire as part of its role as a Dementia Demonstrator Site. Scotland's three demonstrator sites were used as test-beds for innovative new ways of improving care and support for people with dementia.



Picture © Olivier Coupry

Above: Arlene Crockett (left) and Paul Callaghan with Magda Aelvoet, King Baudouin Foundation. Below: members of the Foton Choir.



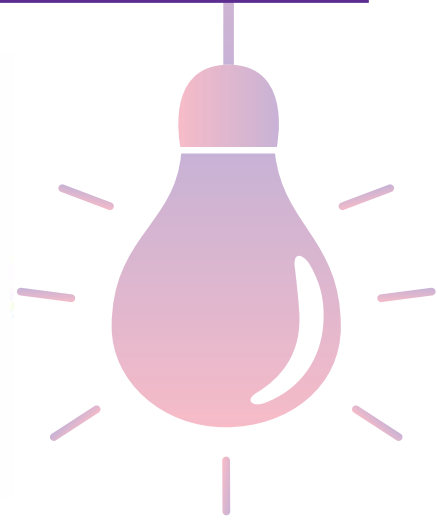
Picture © Olivier Coupry

The theme of the awards was 'Living well with dementia in the community'.



Innovation, Research & Technology in Dementia

Dementia Awareness Week
conference 2014



The 2014 Dementia Awareness Week conference brought leading scientists, politicians and thinkers together to debate ways of improving standards of care for people with dementia. The panel described a range of exciting technological, scientific and social innovations that are changing the way we think about dementia.

Alex Neil, Cabinet Secretary for Health and Wellbeing, began with a video message describing Scotland's world-leading record on dementia care, while also acknowledging that 'very considerable challenges lie ahead'. Geoff Huggins (Scottish Government) followed up with a description of his vision for integrated health and social care, based around asking people 'What matters to you?'

instead of simply 'What's the matter?'. This is the approach developed by Jennifer Rodgers a paediatric nurse who won the Nurse Prize at the Scottish Health Awards in 2013. Geoff challenged the audience to tweet at least 50 messages with the hashtag #WMTMDementia before 11 o'clock to get the 'What matters to me' message distributed far and wide.

The next speaker was scientist Frank Gunn-Moore from the University of St Andrews. He described the exciting research his team are pioneering to help understand how the brain creates memories, and his goal of developing techniques that will have practical benefits for people with dementia.

Henry Simmons introduced Alzheimer Scotland's Next Big Idea challenge, with

three finalists vying to win funding for their technology project. Videos of the three projects followed, and delegates readied themselves to cast their votes later in the day.

The packed opening session was brought to a celebratory climax with the launch of Dementia Friends in Scotland. Following an introduction by Henry Rankin (Scottish Dementia Working Group) and Caroline Brown (National Dementia Carers Action Network), the audience joined Musical Minds for a rousing rendition of 'With a little help from my friends'.

The rest of the day featured a packed programme of eight break-out workshops, a debate on dementia-friendly environments, and an announcement of the winners of The Next Big Idea.

The Next Big Idea

We launched our Next Big Idea competition in spring 2014, inviting proposals for innovative technology projects that had the potential to improve the lives of people with dementia. We received entries from individuals, groups, students, the public and private sectors, and narrowed these down to three finalists. The winner would receive funding of up to £15,000 if they were selected by the audience during our conference.

DEEP connections put forward a proposal to help people with dementia engage with mobile and touch-screen technology. **Memory Match** have created a project that uses games as intergenerational reminiscence tools. **Your Virtual Garden** helps people with dementia engage with a local community garden, either remotely via an iPad or in person.

During the opening session of the conference, each of the three projects screened a video outlining the benefits of their project, and delegates then had the chance to meet them in person in the Tech Zone during the breaks. Once they'd decided which project they thought merited the prize, delegates voted at our old-fashioned polling booth. When the result was announced at 4.20, news quickly spread via Twitter!



Alzheimer Scotland @alzscot

the votes are in and the £15K winner is YOUR VIRTUAL GARDEN #DAW2014

Dementia-friendly environments: the big debate

Our Dementia Awareness Week conference included a debate comparing two different types of dementia-friendly housing. Yvonne van Amerongen described the De Hogeweyk dementia village in the Netherlands. Kate Fearnley (Deputy Chief Executive of Alzheimer Scotland) made the case for Croftspar Place Services in Glasgow. Croftspar is made up of eight single storey flats where people with dementia can live with personalised support. De Hogeweyk provides accommodation for around 150 residents who live in 23 communal houses, with six or seven residents per house.

There was lively discussion about the pros and cons of each approach. Yvonne began the debate, explaining that the residents she cared for had advanced dementia and were no longer capable of living at home. She explained 'The best ward is home, but sometimes that's not possible any more'. De Hogeweyk residents have an average age of 84, and lack the capacity to make decisions for themselves: they each have a nominated relative or guardian who acts on their behalf.

De Hogeweyk is modelled on a traditional Dutch residential neighbourhood, with a supermarket, cafe and theatre. Yvonne explained that 'The surroundings support you to do the things you know, and you feel safe'. During a workshop in the morning, she had explained that she began thinking about the De Hogeweyk model in 1992 after her father died. At the time she was the manager of a care home, but found herself saying 'Thank God dad didn't need to go into residential care'. This realisation prompted her to talk to staff, residents and families about an alternative approach that would be less institutional and more familiar for those with advanced dementia. The first version of De Hogeweyk was opened a year later within a traditional four-storey concrete nursing home. Despite the less than ideal building, staff were able to create a setting where residents were happier and more relaxed. The purpose-built complex that exists now was developed afterwards.



Yvonne van Amerongen

'The best ward is home, but sometimes that's not possible any more'.

Dementia Awareness Week 2014

Dementia Awareness Week 2014 ran from 2-8 June, with a huge range of events taking place all across Scotland. One of the highlights was our conference in Glasgow on 6 June, exploring 'Innovation, Research & Technology in Dementia'. Over 400 delegates took part in a packed day that included the launch of Dementia Friends in Scotland, a vote on The Next Big Idea, and a selection of eight breakout workshops. Those who couldn't be at the event took part in a lively conversation throughout the day and afterwards on Twitter.



..... **FACT FILE**

..... **FACT FILE**

Name: Croftspar Place Services
Location: Springboig, near Glasgow
Model: Supported tenancies in 8 flats with one bedroom, living room, kitchen and bathroom, grouped around a shared garden
Established: 2005

Name: De Hogeweyk
Location: Weesp, The Netherlands
Model: 23 houses (6-7 residents in each) in a self contained complex including a supermarket, theatre, cafe and outside spaces
Established: 1993

Kate Fearnley went on to compare De Hogeweyk with Croftspar Place in Glasgow. She began by saying that she and Yvonne agreed on many things, like the principle of a house with a front and back door, and unrestricted access to outdoor activities. However, while Yvonne painted a persuasive picture of life at De Hogeweyk, it represented 'modified normality' and was 'creating a fantasy reality for people to live in'.

Croftspar Place provides supported housing, and the people who live there come from the local area. This helps keep them rooted in their own community and their own normal life. Family members often say that they 'feel like they've got their relative back' after they move to Croftspar, because many residents blossom once they are given the opportunity to live independently, with staff on site to support them when required. Like Yvonne, Kate also described her own family's experience of residential care. She talked about her father, who used a local care home for respite which was very embedded in the life of the village it was in. However despite knowing many of the residents and staff, he had absolutely no desire to move into the care home. 'To him, it wasn't a natural living situation, connected to the community as it was. He had no wish to live with all those other people, with care staff coming in and out of his room, without his own kitchen where he liked to cook curries.' For him, the next best option to staying in his own home could have been somewhere like Croftspar where he could live independently with support.

Following the debate, members of the audience asked questions, including how each of the two models was staffed, and how they responded to behaviour that challenged. Kate described how a long-term resident of Croftspar, who had previously been very unhappy in a care home and who staff struggled to work with, had been transformed by the ability to resume an independent life in her new flat. Yvonne talked about how the healthy daytime routine at De Hogeweyk – with abundant access to normal, outdoor activities, like shopping – meant residents slept soundly at night and the whole complex only required five night-time staff.



Kate Fearnley

'Residents at Croftspar come from the local area and can stay rooted in their own community and their normal life'.

Owen @microcuts_22

#DAW2014 interesting debate around dementia residential models. De Hogeweyk model vs integration within communities.

Catherine Thomas @Cat_Thomas

Croftspar Place in Glasgow cited as example of supporting people to live their own normal life in their community by @Kate_Fearnley #DAW2014

Jean Armitage @Jean5724

Voting now @alzscot conference where would you choose to stay Croftspar or Dr Hogeweyk?

Alison Petch @icyprof

60% for De Hogeweyk; 40% for Croftspar - but apples and pears? Surprising... #DAW2014

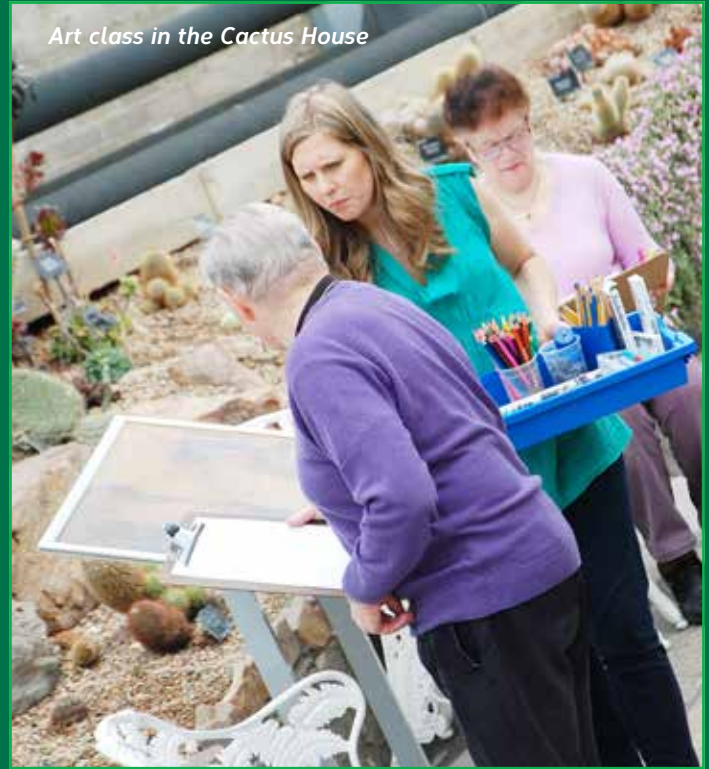
Wigtownshire schools story competition

Over 200 children from across Wigtownshire recently wrote stories for a competition run by Alzheimer Scotland for Dementia Awareness Week. An awards ceremony was held in Wigtown on 4 June, and six children in two age groups received prizes. The photo shows Alzheimer Scotland's Regional Manager Julie Sinclair with the winners in the 10-12 year category. Left to right: Merryn Walker, Leswalt School (first prize); Kayleigh Ross, Creetown School (second prize); Neve Stelling, Drochduil School (third prize).





Information stands on Telecare and Alzheimer Scotland



Art class in the Cactus House



Dancers from Citymoves



Bank of Scotland volunteers take a selfie!



The walking football team



Retro rhythms



Paul Hudson and volunteers at the info bus

Photos courtesy of Arthur Gill, Park Ranger at Duthie Park and Alzheimer Scotland volunteer

A day at Duthie Park

One of the many events that took place during Dementia Awareness Week was an action-packed day in Duthie Park, Aberdeen. There was a huge range of activities on offer with something to suit every taste. The event also raised awareness and funds for the work we do. Thanks to everyone who made the day such a success – the pictures speak for themselves!



Memory Box launches 'Our Big Box'

During our Dementia Awareness Week Conference, The Memory Box Network (a charity focused on digital technology) launched a new online resource called 'Our Big Box'. Developed using the principles of traditional reminiscence therapy, the ground-breaking digital platform enables people to collect and share photograph and other materials online to help facilitate meaningful connections between people with dementia, their families and care givers..

More info

<http://ourbigbox.com>
www.memoryboxnetwork.org



24th Annual Conference of Alzheimer Europe Glasgow, 20-22 October 2014



Are you
eligible for a
Life Changes Trust
award? See page
10 for details.

The theme for this year's conference is
'Dignity and autonomy in dementia'.
Discounted places for Alzheimer Scotland
members can be booked using this link:
www.alzscot.org/europe

Masterclasses: 23 October 2014

Conference delegates are invited to attend one of five
masterclass events on Thursday 23 October. These will
provide insights into specific changes and strategies that
have been implemented within Scotland and England.
Masterclasses are FREE OF CHARGE but
places are limited. To find out more visit
www.alzscot.org/masterclasses



‘People think dementia is a normal part of ageing’

Wendy Watson's father was diagnosed with early onset dementia in the early 1990s. A decade later – after he had died – his wife developed dementia too. Here Wendy and her daughter Hannah – a medical student – talk about their experiences of dementia as a family.

WENDY

My father was about 60 when he first started showing signs of memory loss. By the time Hannah was born he'd been diagnosed with dementia. We don't have many photos of Hannah with her grandfather because we stopped taking photos over time – not consciously, but just because there was less of my dad there.

Mum was able to support dad at home during most of his illness, but he spent the last few months of his life in a care home. There's a similar age gap between my two girls and me and my sister. I remember taking them to the nursing home and him saying 'Here are my girls'. He definitely thought the two blonde girls coming to see him were his daughters, not his granddaughters. He was naturally quite a joker and Hannah and her sister didn't realise he'd really got them confused with me and my sister.

Because we lived 200 miles away from my parents the girls didn't see some of the more difficult things, like when dad got more frustrated and angry. We shielded them from the more distressing situations. I certainly remember towards the latter stages my mum couldn't manage him physically any more. He was past the stage of rationalising and you couldn't talk him out of things. He'd been a lorry driver and would do things like stack furniture in the care home. He was going back to his job.

I think being a nurse gave me a better insight into dad's illness. I remember mum thinking he was being silly or difficult, but me saying it's just part of his illness. I could rationalise his behaviour and better understood how to deal with his frustration, like trying to distract him rather than having a logical argument that he couldn't deal with. It didn't make it any less distressing to watch him fade away, but being

able to understand his behaviour made it a bit easier.

Mum was formally diagnosed with dementia about 2007 but had started showing symptoms several years before. Despite that, many of her skills stayed with her for a long time. She was great at baking and never weighed anything: it was just a spoonful of



this and a spoonful of that. Even after her memory became quite bad she could still bake because this was a real learned behaviour.

Despite her experience with dad, I don't think mum ever thought she was getting dementia: she just put the changes down to old age and forgetfulness. She never said 'I'm going to end up like your dad'. She didn't get frustrated like him either: she accepted it more. Mum managed to live at home and carry on doing things like going to the shop, even when her dementia got relatively severe. It was easier because she lived in a village. Latterly she did

Being a nurse gave me a better insight into dad's illness but it didn't make it any less distressing to watch him fade away

have a full-time day care package but this was mostly just to keep an eye on her.

Mum's now in a palliative care situation at the end of her life. We're experiencing the issues that carers have to face first-hand: discussions about end of life decisions and the challenges that raises for a person with dementia. We've realised that making things like the 'do not resuscitate' decision is the easy bit. Mum weighs five stone now and her malnutrition is dreadful – just because of the debilitating illness, not because of the care she's receiving. We're also struggling with pain relief. Mum's not able to communicate verbally, and trying to ascertain if we think she's in pain is a

real challenge. It's really helpful that Hannah has a shared understanding of these difficult issues.

There's a real timing issue when it comes to discussing end of life care and it's very easy to miss the boat. Once you realise there's something that needs to be said it's often too late. Talking about end of life is very challenging. It's also not something that was discussed by mum's generation. They never realised they had any options and these weren't discussions that they had.

That whole grieving process of losing a person over a long time is hugely challenging. The grandmother Hannah knew and loved has gradually left us.

There's a real timing issue when it comes to discussing end of life care and it's very easy to miss the boat. Once you realise there's something that needs to be said it's often too late.



HANNAH

My grandfather was diagnosed with dementia before I was born, and my memories of him are really quite distant. Sometimes I wonder if the ones I do have are from photos. I don't think the idea of him having an illness crossed my mind at the time. I do remember when he was in the care home he called me and my sister Susan and Wendy, which are my mum and her sister's names. I was five at the time and it wasn't until years later that I understood why. At the time I just thought he was trying to be funny.

People think dementia is a normal part of ageing that happens to everyone and it wasn't until I did my dissertation that I understood it's not. Despite that, a lot of my peers still don't understand dementia fully, even though they are medical students. It's worrying that even third year medical students don't understand

it. We're taught much more about the scientific aspects of dementia: things like what proteins are deposited in the brain. We're not taught about actually being able to deal with a patient with dementia.

Dementia and care of the elderly medicine is definitely something most students shy away from. It's not glamorous like surgery. I was at a discussion group the other day and we were talking about why dementia has such a stigma. The conclusion was fear. People don't want to talk about it or address it because it does turn someone into a completely different person.

We spent a lot of time with my gran (we always called her Nannie) when we were young, and it wasn't until I was in my mid teens that she really started to show the signs of dementia. The thing we spent the most time doing with her was baking. We loved

It's worrying that even third year medical students don't understand dementia.

it. It was something we could do to relax together before she became too unwell.

My memories of my mum and my grandmother are that they were always out in the garden together. It's something they shared a passion for. Me and my sister wanted to spend time in the kitchen but my auntie and mum were out in garden with Nannie!

My grandmother's dementia developed slowly and I think I was more aware of it than my cousins. We lived in Scotland so visited less frequently, but they saw her nearly every week. Because of the longer gaps we could see the decline more easily.

I did an elderly care placement just before Christmas last year and a lot of my peers were wishing me luck beforehand. At this stage in our training we want to learn as much as possible from patients and that includes examining them and taking their histories. When a person with dementia gives you their medical history it's often difficult to get what you want from them as a student. A lot of students don't know what to do when confronted with this situation and a lot have said their elderly care placement was their worst one, but I absolutely loved it. We've just had Dementia Awareness Week at the hospital and I went along to a couple of the talks. I was one of the only medical students there out of 300, which is quite telling.

My mum and her sister are having to make end of life decisions for my grandmother at the moment.

There's such a fine line between when to treat someone and when not to. It's so blurred. It's difficult to know whether providing the simple things we all need for everyday life like food and drink is the same as actively treating someone. These are really difficult questions to answer.

Nannie wasn't even aware she had dementia and her illness has been a ten year process. When someone's just showing a few signs of memory loss, I don't know if you can ask them if they want to be given antibiotics if they get an infection in ten years time. No one would have predicted the current situation ten years ago. Nannie doesn't recognise us. She can't speak and she can barely swallow. If my mum and aunt, who are both nurses, didn't realise that, I'm not sure how other people are supposed to be able to prepare themselves.

Nannie's illness is almost a double blow because we've already accepted she's not really our grandmother any more: not the lady she once was, but it's going to be a second kind of grieving process when she does pass away.



Dedication

My lovely Nannie passed away a couple of days after my mum and I gave this interview. In many ways, we lost her in spirit a long time ago but that didn't make losing her physical presence any less hard. Despite this, we are glad we can now focus on the vibrant, loving woman she used to be and remember the many, many happy times we shared together.

Hannah Watson

First Members' Advisory Forum: "Well worth attending!"

Alzheimer Scotland's inaugural Members' Advisory Forum was held in Edinburgh on 30 April this year. As this was the first session, we were testing out a new style of engagement with our members and were unsure what kind of response we would get. We needn't have worried – we were oversubscribed really quickly so members were obviously keen to participate.

On the day, members heard presentations on innovations (including the Dementia Dog project); end of life care (ethics and rights); our proposal for an early diagnosis and awareness campaign; and dementia friendly communities. After each presentation,

members were invited to discuss some key questions and feed back via a facilitator. There was a lot of lively debate and discussion around the tables and, although there were differences of opinion or emphasis, there was broad agreement on how we should proceed with our work in these important areas. In particular, members gave us a very strong steer as to how we should take forward our early diagnosis and awareness campaign.

One clear message coming from the feedback is that people appreciated the numbers being kept small. "I enjoyed meeting members from all over Scotland on a smaller scale than at

Annual Conference. It was great to have the opportunity to share learning and experiences". "It was a small group but that made it easier for everyone to have their say."

We have now planned our second forum to take place in Stirling on 30 September so please consider coming along, especially if you have a particular interest in one or more of the topics on the agenda.

'There was a lot of lively debate around the tables, but broad agreement on how we should proceed with our work'

Autumn Members' Advisory Forum

We are holding our second Members' Advisory Forum on Tuesday 30 September 2014 at The Stirling Highland Hotel.

The forum will enable Alzheimer Scotland members, stakeholders and advisers to explore and better understand current issues and to test new ideas. We aim to capture key thoughts, discussions and themes emerging on the day to feed into future planning.

To book your place (members only), go to www.alzscot.org/maf. If you do not have internet access, contact Mark Leiper, Membership Officer, on 0131 514 0007 or write to him at 22 Drumsheugh Gardens, Edinburgh, EH3 7RN.

We had a wonderful response to the first forum in Edinburgh in April. Places are limited so we recommend that you book early.

Programme for 30 September 2014

09:30-10:00	Arrival tea & coffee and a chance to meet other members.
10:00-10:15	Welcome and introduction from Henry Simmons, Chief Executive, Alzheimer Scotland.
10:15-11:15	First Session: Early diagnosis. How to encourage people to come forward and what would an early diagnosis campaign look like.
11:15-11:30	Coffee & comfort break.
11:30-13:00	Second session: The cost of care and how to pay for it.
13:00-13:45	Lunch and networking.
13:45-14:45	Third session: Research priorities - which areas should we be focussing on?
14:45-15:00	Closing remarks.

Elly's still volunteering at 92!

Alzheimer Scotland volunteer Elizabeth Lillie recently celebrated her 92nd birthday, but despite that she's still a loyal member of the volunteer team at the 2nd Best shop in Golspie!

Elizabeth, known as Elly, works in the shop, which raises funds for Alzheimer Scotland, on Monday afternoons and Saturdays. In between, she prepares new stock so it's ready to go on sale, washing donated soft toys and attaching pieces of jewellery to cards ready for display. Elly's daughter Brenda MacMillan, is the manager of the shop.

Elly's late husband Herbert had dementia and Brenda set up 2nd Best in memory of her dad to help raise funds for Alzheimer Scotland. The shop is an important part of the local community and raises an incredible £50,000 a year.

Elly was born in Germany and her family came to London at the start of the Second World War. When Brenda moved to Scotland in the 70s, to run a

bed and breakfast in Banff, her parents joined her too. Elly's father ran a bicycle shop in Cologne and Brenda puts her mum's wide range of practical skills down to what she learned in the family shop all those years ago.

Acknowledging Elly's landmark birthday and the wonderful work she does for Alzheimer Scotland, Kate Fearnley, Deputy Chief Executive, said: 'As far as I know Elly is Alzheimer Scotland's oldest volunteer, and I hope she isn't thinking of retiring yet! Over the years all her work has contributed greatly to the success of the shop.'



Picture: Louise Mackay

Elly Lillie pictured with her daughter Brenda MacMillan (left) and fellow volunteer Wendy Rowe.



Dementia Helpline celebrates 25th anniversary

Helpline volunteers and supporters old and new gathered in Edinburgh on Saturday 7 June to celebrate the 25th anniversary of this flagship service. Coming at the end of a very busy Dementia Awareness Week, guests were treated to a relaxed, informal barbecue in the lovely setting of the gardens beside our National Office. An extra treat was the wonderful music supplied by students from our close neighbours, St Mary's Music School, courtesy of their Director of Music, Paul Stubbings.

Kate Fearnley, Deputy Chief Executive, paid tribute to all the Helpline volunteers and staff who, over the years, have responded to calls from almost 90,000 people, including a growing proportion of people with a diagnosis of dementia. The Helpline is a service very close to Kate's heart as she managed it for many years and has seen it grow in impact and reach in that time.

Current Helpline Manager Elaine Harley spoke about some of our

longest serving volunteers, including one, Bronwen Jones, who has been with the Helpline for 20 years and who had volunteered to cover the line so others could come to the party. She then invited one of our oldest volunteers Liz Marshall and one of our newest volunteers Steven Dick to cut a 25th anniversary cake, complete with telephone!



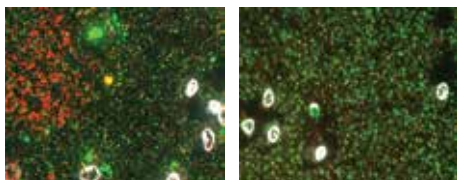
Alzheimer Scotland research news

Lindsay Kinnaird, Alzheimer Scotland's Research Manager (pictured below), provides an update on our research work, including key approaches we are taking and some of the projects we are funding.

Alzheimer Scotland Dementia Research Centre, University of Edinburgh

Alzheimer Scotland's Dementia Research Centre at the University of Edinburgh is now in its third year and has made remarkable progress in this short time. Led by Professor John Starr, it has established an impressive programme of work and international collaborations. A key focus of research relates to the emerging theme of investigating the impact on dementia when "scaffolding" is taken away. This theme is being explored at the molecular level right up to what happens in social life.

In Alzheimer's disease the connections between brain cells that transmit signals (synapses) are gradually damaged and lost. Dr Tara Spire-Jones is using new techniques to see what is going on with these synapses using brain tissue donated to the Brain Tissue Bank. The images below are of a healthy older adult and a person with Alzheimer's disease.

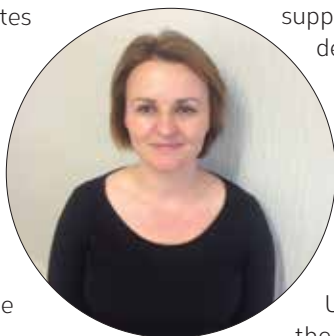


Alzheimer's disease Healthy older adult

Red shows up amyloid, a protein thought to cause damage in Alzheimer's disease and the white shows up cell nuclei, where the cell's instructions are kept. However, most striking is the lack of green, which represents "post-synaptic density", and its changed distribution in Alzheimer's disease. This "density" is attached to cell membranes, which receive messages.

in order to support both proteins that receive these messages (receptors) like a piece of scaffolding and proteins that then pass the signal on into the interior of the cell. In the image of Alzheimer's disease, it is as if most of the scaffolding has been taken away so that the synapses can no longer work properly.

Dr Tom Russ (pictured right) and Dr Ruth Sibbett are currently investigating whether the scaffolding of social support can protect against developing dementia.



Tom was the Alzheimer Scotland Clinical Research Fellow from 2009 to 2013. He has now been appointed Clinical Lecturer in Old Age Psychiatry at the University of Edinburgh – the only post of this kind in

Scotland. Ruth has now taken-over from Tom as Clinical Research Fellow at the Centre.

Lucy Hiscox is conducting her doctoral study on loss of scaffolding and other changes to the brain structure with a new brain scanning technique of Magnetic Resonance Elastography. This work is based on the fundamental physical property that some materials "wobble" more than others. It is thought the parts of the brain that have lost scaffolding will wobble more.

Over the next few years this research, along with the work of other researchers at the Centre, will provide direction to understanding what more can be done to keep the scaffolding in place in dementia.

Alzheimer Scotland Policy & Practice Centre, University of the West of Scotland

The Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland was launched in

December 2012. Led by Professor Debbie Tolson, its aim is to advance dementia policy and practice through education, research and social enterprise. The Centre has welcomed its first three doctoral students whose research will focus on complementary therapies for care home residents with dementia, enhancing compassion and care within acute hospital wards for patients experiencing hyperactive delirium and environmental interventions in dementia care.

The current focus of the Centre's funded research includes the potential for continued employment with dementia, development and assessment of football-based reminiscence therapy and the role of enhanced sensory day care in advanced dementia. In addition to this, Professor Graham Jackson is conducting a study along with the Mental Health Tribunal Service. The work will focus on the experiences of people with dementia and their supporters of the Mental Health Act and the Tribunal System. Please contact Graham if you have any experiences you would like to share (Graham.Jackson@uws.ac.uk).

Some of our other research projects

Developing our understanding of day care

Dr Louise McCabe from Stirling University is undertaking a project with people with dementia and their supporters to understand their views and experiences of day care services in Scotland. During the research Louise will talk to 20 people with dementia alongside their main supporter. These interviews will explore individual experiences of attending day care services and ask about the changes people have experienced since attending. Supporters will be asked about the impact of day care services from their perspective and how they feel it

has helped them and the person they support. The research is being done in parallel with a similar project in Norway and at the end of the research it will be possible to compare experiences between the two countries.

Playlist for life

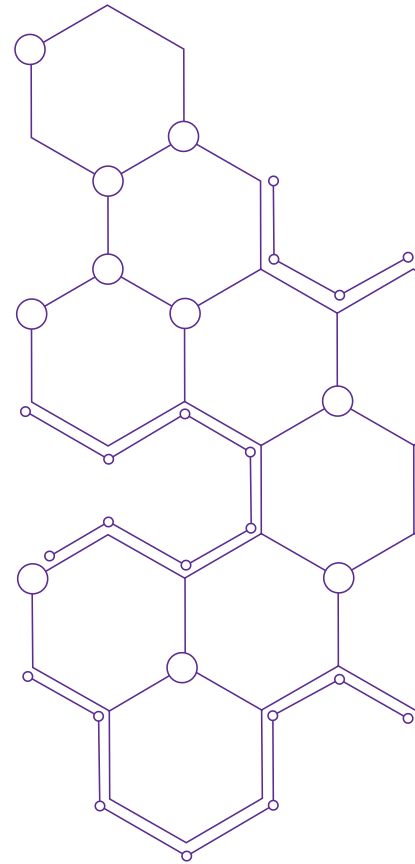
Music psychologist Gianna Cassidy at Glasgow Caledonian University is leading a pilot study on evidence based music intervention for people with dementia. This work involves reviewing evidence and developing a pilot guide for constructing an individually tailored playlist. The project also involves putting together two large scale grant applications to further understand the role music can play in supporting people living with dementia.

Design Fellowship

An application has been made to the Arts and Humanities Research Council to fund a Design Fellowship. We hope this will result in Paul Rodgers, Professor of Design Thinking at Northumbria University, joining Alzheimer Scotland for one year. Paul's work will focus on the role of design in engaging people in the early stages of dementia in positive ways that re-build self-esteem, identity and social participation.

More info

I would be happy to hear from you if you have any questions about this article or would like to hear more about Alzheimer Scotland's research activity: Lindsay Kinnaird, Research Manager, Tel: 0131 243 1453, lkinnaird@alzscot.org



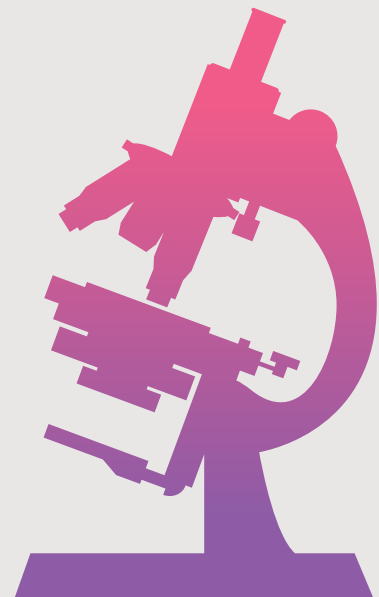
"I am very grateful to Alzheimer Scotland for their funding and encouragement at the start of my career" (Dr Tom Russ)



Donating brain tissue to dementia research

Many people with dementia and their families are keen to aid dementia research and one way to do this is by donating brain tissue after death. The Brain Tissue Bank at the Alzheimer Scotland Dementia Research Centre can process donations which will contribute to our understanding and treatment of dementia in the future. We can also accept donations from those who no longer have the capacity to give informed consent, via next of kin, attorneys or guardians.

If you are interested in becoming a donor please contact the Alzheimer Scotland Helpline on 0808 808 3000. For more information you can also visit our website at www.alzscotdrc.ed.ac.uk



Suraya's multicultural dance fundraiser

Alzheimer Scotland supporter Suraya Ahmed recently organised one of our most colourful fundraising events ever. Called 'A thousand and one nights', it featured Egyptian, jive, Bollywood and Spanish dancing. The show was staged at Eastwood Park Theatre, Giffnock, on 10 May and was described as 'Eastwood's answer to the Royal Variety Performance!'

Suraya is an experienced dance teacher and runs classes in Glasgow and Renfrewshire. She organised A thousand and one nights in memory of her mother, who had dementia. Her show included a slide show about Alzheimer Scotland's services, along with a raffle. Money was also raised from ticket sales. Suraya spoke to our regional fundraiser, Bronwyn O'Riordan, about the event:

'The show was an all-singing, all-dancing extravaganza that gave my students a chance to perform on stage. I enjoyed every minute of it, and judging by the amount of noise the audience made it was well received by them too. It was a great buzz knowing we were helping to raise awareness of dementia, as well as funds for Alzheimer Scotland. My students really felt the excitement and enjoyed showing off all their hard work on stage.'

I decided to organise the show as my mother had dementia. She was finally diagnosed at the age of 81 and died when she was 87. I saw the terrible impact the illness had on my mum as we watched her disappear before our eyes.

Everyone needs to be aware of dementia, and how it affects families and carers too. I'm hoping that by raising money and awareness we can make life a little more comfortable for other families living with dementia.



Suraya and her daughter Karyn

I'm so grateful to everyone who supported me to put the show on, in particular my husband Mac and my children Karyn, Chris and Jordan. We also received lots of generous donations from companies for the raffle.

One of my students, Tracy McCartney, arranged all the sponsorship and also raised £375 herself. The grand total we raised for Alzheimer Scotland, after paying for the venue, was just over £2,000.

Ian's run for Alzheimer Scotland

On 12 April 2013 Ian Wilkie lost his father, Alistair, to complications associated with vascular dementia. Exactly a year later, Ian organised a 10K run round Arthur's Seat in Edinburgh. He completed the run with Alistair's four grandsons, Elliot, Grant, Jamie and Craig, along with other friends. Between them they raised an amazing £7,600. 'Alzheimer Scotland supported my mum throughout dad's illness and we wanted to raise funds so they can help others in the same situation. Dad and I both went to George Heriot's School in Edinburgh (the photo shows Alistair Wilkie in his school uniform), as did my wife Fiona and many of his friends. Because of this, we decided the school would make the perfect start and finish point for the run. Our 10K route included the fearsome Radical Road which follows the route of Salisbury Crags. Many thanks to everyone who supported us – we were delighted with the total raised.'



Comic fans' podcast raises funds for Alzheimer Scotland

Comic fans Alistair (Al) Kennedy and Paul O'Brien recently recorded an episode of their podcast*, called 'House to Astonish' in front of a live audience at the City Cafe in Edinburgh. The pair donated proceeds from the ticket sales to Alzheimer Scotland.

Al and Paul have an international fan-base, and their podcasts have been downloaded more than 100,000 times this year alone. House to Astonish focuses on the world of comics, with reviews, opinions and the latest news for fans. Al explains: 'In 2009 Paul and I started thinking about whether it might be fun to do one of these new-fangled podcast things. A short time after that, House to Astonish launched, and now we're nearly five and a half years down the line.'

Al recently lost his grandfather to dementia, and he and Paul decided to host a special live show to raise funds for Alzheimer Scotland (they normally record the podcasts in Al's flat). He explains: 'One of the ambitions I'd had for

a long time was to do an episode in front of an audience. Knowing that I was going to be a father soon, and with Paul having recently become a father himself, I figured that it was now or never. Around that time, I lost my grandfather to dementia, and it was the decision to donate all the profits from the live show to Alzheimer Scotland that really got us motoring on making the idea into a reality.'

At the last count, this novel fundraiser had raised over £700 for Alzheimer Scotland, a fantastic achievement.



'A podcast is an internet-based broadcast that people can listen to online or download to a music player'

More info

www.housetoastonish.com

TSB Hike it Or Bike it Challenge raises £25,000

On Friday 28 March, intrepid TSB employees across Scotland walked or cycled to work as part of the TSB Hike it Or Bike it Challenge. By leaving their cars at home, shunning public transport and holding bake sales, raffles, collections and competitions throughout the day in branches, TSB staff and generous customers managed to raise a phenomenal £25,000 for Alzheimer Scotland.

We are truly grateful for the amazing support shown to Alzheimer Scotland by TSB staff and customers over the past year as part of our 'Charity of the Year' partnership. Colleagues in branches and offices throughout Scotland have proven to be exceptional fundraisers, raising over £120,000 so far.

The money raised by TSB is helping us to deliver the 'Live Well' programme designed to educate people with dementia, their partners, families and carers about how to cope with day to day life and how to plan for the future. This first ever national support programme will make a big difference to families across Scotland, helping us to make sure that nobody faces dementia alone.

Baxterbear teamed up with TSB to help their fundraising effort!

90th birthday donation tops £1,000

Alzheimer Scotland recently received a donation of over £1,000 made by John Alexander in memory of his late wife Jenny. Jenny was diagnosed with dementia in 2004 and was cared for by John at home until she passed away in 2008, shortly after the couple's 60th wedding anniversary. John celebrated his 90th birthday on 28 March this year and asked his family and friends to make a charitable donation instead of buying presents. With help from his daughter-in-law, Jacqui George, John selected Alzheimer Scotland as his charity of choice. He has asked for the donation to be split between our Dementia Research Centre and Alzheimer Scotland's local services in John's home town of Aberdeen. We are extremely grateful to John and his family for their generosity.



Jenny and John Alexander



Blisters galore – but no midges!

Lewismen complete amazing Hebrides Memory Hike

Imagine walking 150 miles in five days through some pretty horrendous weather and difficult terrain – what could possibly motivate anyone to take on such a challenge? How do you train for walking 30 miles a day for five days on the trot? Part way through their walk from Castlebay on the Isle of Barra up to the Butt of Lewis, I expect John Maciver and his nephew Kevin Smith may have questioned the wisdom of their plan but they dug deep and carried on.

John now lives in Fife but still has family in the Western Isles and he and Kevin wanted to do something to raise the profile of Alzheimer Scotland and as a mark of respect to their family members who have had dementia or who are currently living with dementia. Helped by their friend Kenny MacIannan who drove their support vehicle, made sure they were fed and watered and helped organise first aid, foot care and massages along the way, the Hebridean Hikers also enlisted the help of other family members who walked part of the way with them.

We had intended taking our Memory Bus to accompany the men but couldn't make it to Barra in time for the start of their walk on 12 May so we decided to follow on a couple of days later, catching up with them on their final day. On our journey through the islands we heard from people who had been following the Memory Hike on Facebook and Twitter and there were several tales about poor Kevin's feet!

When the last day of the walk arrived, the weather was pretty poor with that constant drizzle that soaks you through to the skin, and a strong wind. We set off on the search for John and Kevin and thought we would catch up with them quickly. After a good few miles I thought they must have gone off the road to shelter for a while as there was no sign but we kept going, then I saw a couple of people on the horizon – it was Kevin with one of his relatives. John was a bit further ahead with another member of the family.

We arranged to meet up with the men at their final rest stop before the last leg of the journey up to the lighthouse at the Butt of Lewis. By this time the sun had decided to peek through so, after a short break for a hot drink and some of their Granny's "Duff" (a really tasty fruit loaf), they set off together, accompanied by our

Service Manager Marion MacInnes and other supporters.

We drove on to the lighthouse, after a couple of wrong turns. Don't believe anyone who says "You can't miss it" when giving you directions.

The sun came out again and it was a great sight to see a crowd of people coming over the horizon ahead of John and Kevin, leaving them to get to the finish line together. What an achievement! Donations are still coming in to their Just Giving page where donors have given over £3,200 online in addition to the many offline donations people gave along the way. It was a real pleasure to play a tiny part in this epic journey – even if it was just to provide a temporary tearoom and first aid station.

Maureen Thom
Information Manager

Read more/donate

www.justgiving.com/hebridesmemoryhike
www.facebook.com/HebridesMemoryHike

Kevin and John's walk raised over £6,500 for Alzheimer Scotland!



'What could possibly motivate anyone to walk 150 miles in five days through horrendous weather and difficult terrain?'



Western Isles Memory Bus Tour

For some time, we have been talking with colleagues about getting one of our mobile information vehicles over to the Western Isles. The Hebrides Memory Hike gave us some extra incentive to organise the trip. Unfortunately other commitments and factoring in ferry times meant we only had three days available for our tour but what a lot of places we visited in that time!

In South Uist our first visit was to Taigh a'Chridhe Uile Naomh, a purpose-built care home in Daliburgh where we met up with Lorna Steele our Dementia Link Worker, Southern Isles. We had over 20 visitors, from care home staff and local paramedics, to three students about to start placements within local care homes. Then it was a quick dash north to meet up with National Dementia Carers Action Network member Myra Lamont and her husband Archie. Myra kindly gave us lunch and talked about her plans for setting up a local dementia interest group in the Southern Isles, with an inaugural meeting during Dementia Awareness Week.

Then it was on the road again to lochdair where we dropped in on what must surely be the smallest care unit in the UK. Run by Tagsa Uibhist, Doigheag Care Home has two beds and can provide long-term or respite care. From there it was on to Benbecula where we visited the Uist and Barra Hospital at Balivanich, before heading to the Tagsa Uibhist offices where we met up with Manager Kathryn Martin and several of her colleagues, local people and journalist Susy Macaulay from the Island News. Tagsa provides an amazing array of services, including home support, a cleaning and handyperson service, community transport and advice on self-directed support.

We had hoped to squeeze in a visit to Trianaid, another care home, at Carinish, North Uist but we were running late and arrived as staff were preparing to give residents their evening meal – not a good time – so it was a quick hello then across to Berneray for our overnight stay, meeting up with Tagsa care worker

Barbara on the way. She kindly drove ahead of us to show us the way to our B&B which was, literally, on the beach.

No time for breakfast in the morning as our ferry to Harris left at 7.15 but our first stop at Leverburgh Care Home kindly gave us bacon rolls to keep us going. They were delicious. After meeting staff there and giving them a range of information we headed to Tarbert for our next stop, trying not to get distracted by the amazing scenery. Day two ended in Stornoway where we planned to meet up with Marion and Chris in our Dementia Resource Centre the next day to stock up



In lochdair we dropped in on what must surely be the smallest care unit in the UK. Run by Tagsa Uibhist, Doigheag Care Home has two beds and can provide long-term or respite care.

on publications as we were running out.

On our last day we spent the morning at the Co-op in Stornoway, where we were delighted to meet our other Dementia Link Worker in the Western Isles, Ann Mackenzie. Before setting off to meet up with the Hebrides Memory Hikers we dropped in to our day centre at Solas where we had lunch and a chat with staff, volunteers and service users who came on board for a look round.

It was a tiring but amazing three days seeing not only the range of services and supports available but also how keen the people we met were to receive information and get further training in dementia care. We covered a lot of ground in a variety of weathers which really brought it home how challenging it must be to reach and support people living in such a remote part of Scotland.

*Maureen Thom
Information Manager*



Memory Walk 2014

Join us on **Sunday 7 September** at **Dalkeith Country Estate** for our **2014 Memory Walk**

Memory
Walk

Keep an eye
on our website
for other local
memory walks
coming up in
your area!



Put your best foot forward for Alzheimer Scotland!

Bring your whole family along and enjoy the beautiful surroundings while raising funds for people living with dementia across Scotland. It will be a fun-packed day with music, entertainment, face-painting, bouncy castle and lots more.

For more information please visit our website
www.alzscot.org or call 0845 260 0789

Making sure nobody faces dementia alone.



**Alzheimer
Scotland**
Action on Dementia