

Dementia in Scotland



Spring 2014 – Issue 82





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Future events

Dementia Awareness Week Conference, 6 June 2014

See pages 14 and 15 for more details

Book online

Book your place by visiting www.alzscot.org/daw2014

24th Alzheimer Europe Conference, Glasgow, 20–22 October 2014

See page 8 for more details

Alzheimer Scotland AGM, 7 November 2014

Alzheimer Scotland's 2014 staff, members & volunteers conference and Annual General Meeting will take place at the Radisson Blu Hotel in Glasgow on Friday 7 November. This will be an opportunity to meet, share ideas and take part in workshops.

More info

For further details please email agm@alzscot.org

Welcome!

This edition of Dementia in Scotland features a true cross-section of the work we are doing as an organisation. It's a celebration of the commitment of our staff and members – and of course our dedicated volunteers and supporters.

On the following pages you'll discover how our Dementia Dog pilot project is making a real difference to the lives of two more families. Also in this edition, Chief Nursing Officer Ros Moore describes the work being done to improve the care of people with dementia in acute hospitals. Much of this is in direct response to feedback sessions organised by Alzheimer Scotland in partnership with the Scottish Government.

Our recent debate on the future of dementia care attracted widespread interest from the public and benefited from the skilled chairmanship of Sally Magnusson. During the debate Sally shared her family's own experiences of poor dementia care and talked about ways to make things better for other families.

Our Relative values feature hears from Henry Rankin, Chair of the Scottish Dementia Working Group and his wife Anne. They share their experiences of living with dementia.

We're proud to highlight the work of some of our volunteers in this issue and plan to include regular updates on the invaluable work volunteers do for Alzheimer Scotland. You'll also discover some of our many staff and read about the ways in which they're helping us meet our goal of making sure nobody faces dementia alone.



Henry Simmons
Chief Executive
Alzheimer Scotland

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Alzheimer Scotland
Action on Dementia



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Winner of Jim Jackson Essay Prize announced

Hannah Watson, a medical student from the University of Manchester, is this year's Jim Jackson Essay Prize winner. The prize commemorates the late Jim Jackson OBE, former Chief Executive of Alzheimer Scotland. Hannah was completing her undergraduate degree at the University of St Andrew's when she submitted her essay, 'A life in another's hands', which uses both research and her own family experience to explore the issues surrounding end of life care for people living with dementia.

'I had written a dissertation on end of life care a few months before. Someone told me about the Jim Jackson Essay Prize and suggested that I enter. I realised there were many aspects that could be applied to my family.'

Hannah describes how 'dementia is, unfortunately, no stranger to my family', affecting both her maternal grandparents. She describes how her grandfather was diagnosed when she was only five years old, 'removing my



Henry Simmons photographed with essay prize winner Hannah Watson

fun-loving and playful granddad and replacing him with an angry, confused man who no longer recognised me'. She contrasts this with her grandmother's diagnosis ten years later, when she was 'old enough to be aware of and fully appreciate the situation'.

More info

You can download Hannah's essay by visiting: www.alzscot.org/essay

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Honorary doctorate for James McKillop

James McKillop, a founder member of the Scottish Dementia Working Group (SDWG), was awarded an honorary doctorate from the University of Strathclyde during a ceremony in November. The award was in recognition for his work in establishing the SDWG, which acts as the independent voice of people with dementia within Alzheimer Scotland. The group is committed to influencing public policies that impact on the lives of people with dementia and their families. It is open to anyone living in Scotland who has been diagnosed with dementia or a related condition. James was chairman of the SDWG from 2002 to 2008 and remains an active member to this day.

Edinburgh bus driver hailed for kindness

Lothian Buses driver, Pawel Gibula, has been hailed as a hero after stopping the bus he was operating to help an elderly woman he suspected may have dementia after finding her walking alone in the middle of the night.

Mr Gibula was driving the late night number 11 service through Leith when he noticed a distressed woman standing behind a bus stop on Newhaven Road. He pulled over to speak to the woman.

The woman couldn't tell him her name or why she was outside. Mr Gibula helped her on to the bus to warm up and waited with her for an hour and a half until police arrived. At the same time he made sure his other passengers were aware of the situation and were able to get the next available bus.

Katie Sellers was a passenger on board the bus and labelled the driver a 'real credit' to his employer. She said she had been left feeling 'grateful and impressed'.

Mr Gibula, a father of two, explained that he noticed the signs of dementia because his late grandmother had lived with the condition too: 'The first thing



Picture courtesy of Edinburgh Evening News

I noticed was that she was an older lady and she was wearing sandals. That shocked me. No one wears sandals in winter at this time of night.

'I stopped the bus, turned the engine off, took my phone and put the address she'd given me into Google Maps. It turned out that it was the exact address where we were, just beside the bus stop. She said: "I'm confused and lost." She

looked distressed – you could actually see it on her face.'

Mr Gibula has reacted very modestly to the positive coverage his actions have prompted, explaining: 'I'm overwhelmed by all the reaction. It was a simple, normal deed. There's nothing extraordinary. Every single person or driver from our company would do the same thing.'



Perthshire family raises £500 in local auction

An auction in Perth and Kinross selling ornaments and furniture has raised £500 for Alzheimer Scotland. The sale was arranged on behalf of Janet Coutts, a well known local pharmacist who was diagnosed with vascular dementia 10 years ago.

Janet, originally from the Oakbank area of Perth, now lives in Bridgeview Nursing Home in Dundee. She enjoyed staying active in her community and remained so even after her diagnosis.

Not long after being diagnosed, Janet asked that a donation be made on her behalf to Alzheimer Scotland when the

family felt the time was right. Janet, and her husband Frank, wanted others living with dementia in Perth and Kinross to receive the information, help and support needed to live with the diagnosis.

Recently, Janet's husband has also been admitted to a care home and their family of four daughters decided to auction some of the ornaments and furniture from their house.

Fiona Matthews, Alzheimer Scotland's Dementia Advisor for Perth and Kinross collected the cheque, which was presented by Janet and Frank's daughter, Frances Swan.



Bank of Scotland becomes first dementia friendly bank

In November, Bank of Scotland (BoS) became Scotland's first official dementia friendly bank. This followed a partnership with Alzheimer Scotland to deliver awareness-raising and information to branch colleagues. Staff at BoS are now able to provide a more dementia friendly service for people living with dementia and their carers.

BoS has also announced its commitment to train staff further on the issues surrounding dementia and to improve its own practices on an ongoing basis.

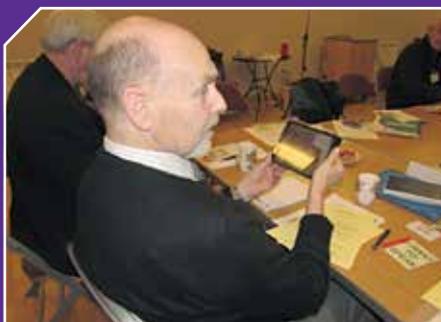
Robin Bulloch, Managing Director of Bank of Scotland Community Bank, said: 'We want to lead the way to help customers affected by dementia. By taking these positive steps and training our staff in dementia awareness, we aim to help make the day-to-day life easier for people with the condition and their carers.'

Alzheimer Scotland Chief Executive, Henry Simmons, added: 'We are absolutely delighted to be able to work so closely with Bank of Scotland in generating this model of dementia friendly banking. Managing money is a major concern for people with dementia, their carers, partners and families. It is vital that the financial sector recognises the difficulties involved and is knowledgeable and sympathetic about the help they can provide.'

Since November, Bank of Scotland branches have started displaying 'Dementia Friendly Bank' window stickers. This is to inform customers that their local branch is committed to delivering dementia friendly banking.

Scottish Dementia Working Group gets connected

At its meeting in Dundee on 20 February, the Scottish Dementia Working Group (SDWG) broke new ground by using the Facetime app on an iPad to connect with one of its members who couldn't attend the meeting. Nancy McAdam, who lives on the Black Isle, was able to participate thanks to the technology. SDWG chairman Henry Rankin was amazed at how easy it was to link up with Nancy and described the experience as 'fantastic'. Nancy was moved to tears as the meeting closed, describing her experience of Facetime as 'just wonderful'. The group is planning to use Facetime and other new technology more extensively from now on to make it easier to connect with each other from a distance.



Dementia Dogs Alex and Vonn start work

Last July two specially-trained assistance dogs were paired with families in Scotland as part of Alzheimer Scotland's Dementia Dog pilot project. Two more dementia assistance dogs, Alex and Vonn, have recently been paired with their new families: Alex & Moira, and David & Maureen.

Alex Whyte was diagnosed with dementia five and a half years ago. Last October, he and his wife Moira were paired with Dementia Dog Alex, a black labrador who has been specially trained to help his human owners with tasks round the house. Alex has also quickly become a much-loved pet who can help reduce anxiety or tension, as well as provide companionship.

Two-year-old Alex does a range of clever tasks like fetching Mr Whyte's medication in the morning and bringing it to him, and leading him to notes when Moira is out. He has been taught to respond to a range of commands, as well as to the sound of a bell. Moira can set an alarm when she is out, and when Alex hears this he will lead Mr Whyte to notes that she has left for him. These can remind him to do things like have a snack or make a cup of tea.

The Dementia Dog pilot project is aiming to show that dogs can bring a range of benefits to people with dementia. Examples include helping them maintain their waking, sleeping and eating routines,



as well as improving their confidence and keeping them active. A Dementia Dog can also provide companionship and reassurance when the person is facing new and unfamiliar situations.

The project began as a Glasgow School of Art service design project which won funding through the Living Well with Dementia Challenge. It has been developed in partnership with Alzheimer Scotland, Glasgow School of Art, Dogs for the Disabled and Guide Dogs UK. The four dogs currently taking part in the project receive regular visits from trainers at the homes of their owners to ensure they stay fully trained.

More info

You can find out more about the Dementia Dogs project by visiting:

www.dementiadog.org



Right: Dementia dog Alex with owners Alex and Moira. Left: Vonn at home with David and Maureen.

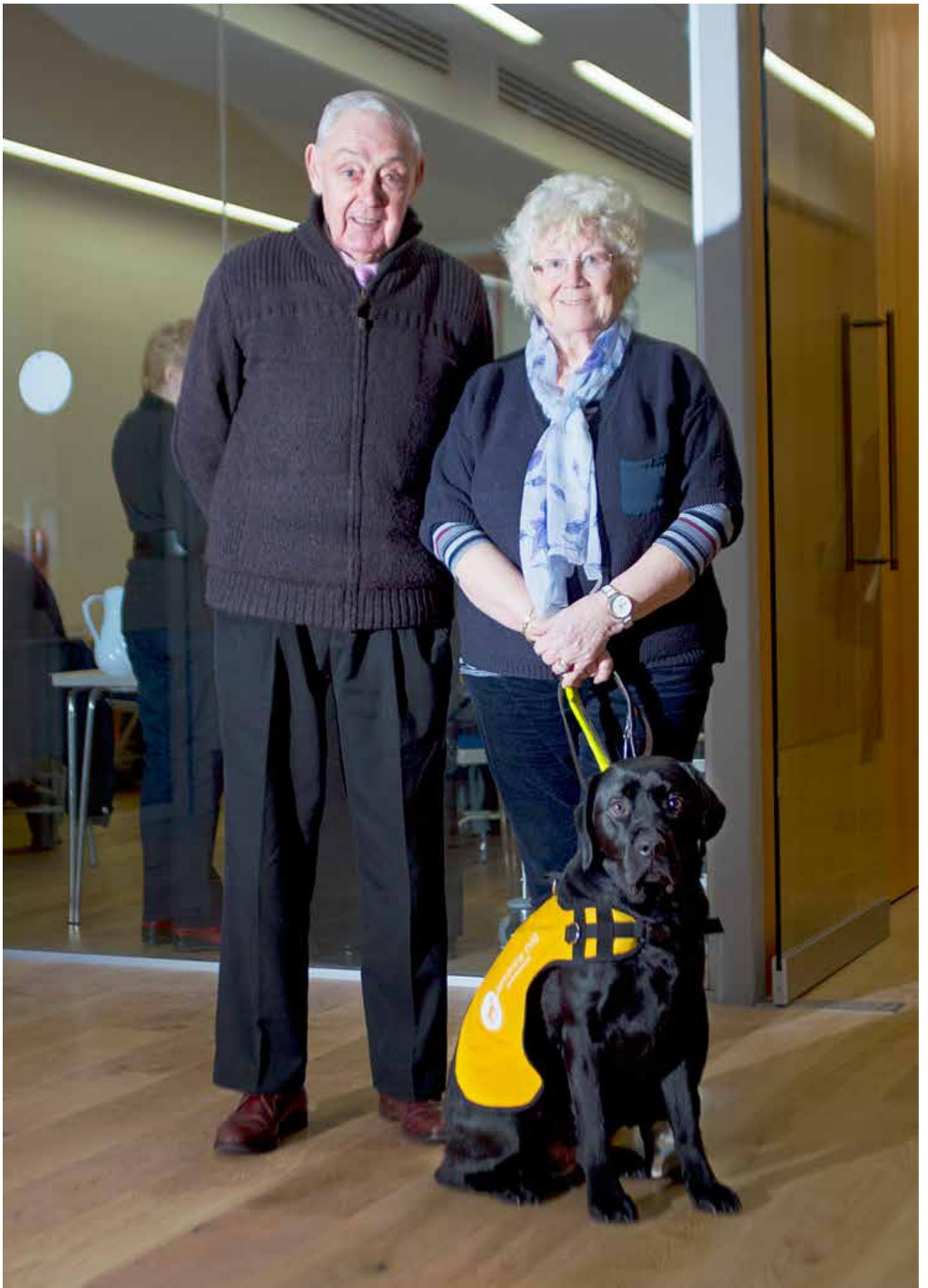
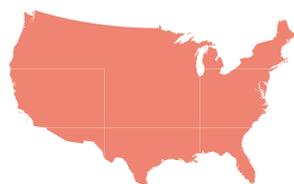


Photo courtesy of Dylan Drummond. www.sonofthesea.co.uk

USA



6 million people watch comedian's dementia plea on YouTube



On 26 February Canadian comic actor, writer and director Seth Rogen gave testimony at a US Senate hearing about the state of Alzheimer's disease research. Rogen delivered a speech detailing his mother-in-law's struggles with the disease and strongly criticised the state of research as well as the public perception of people living with the disease. He called on the Senate committee and the government to take more steps in the fight against Alzheimer's disease.

Prior to his testimony, Rogen had already been involved in Alzheimer's disease advocacy for several years, acting as a celebrity spokesman and fundraiser for the National Alzheimer's Association. He and his wife also started the non-profit organisation, "Hilarity For Charity" to help raise funding for Alzheimer's disease care, support and research as well as awareness of the disease, particularly among younger people.

Watch the video

YouTube

You can view Seth Rogen's speech to the Senate on YouTube using the following link: <http://bit.ly/1gDkNjq>

Over five million Americans have Alzheimer's and at this rate, in 35 years, as many as 16 million will have the disease.

EUROPE



24th Alzheimer Europe Conference to be held in Glasgow



Alzheimer Europe has announced that its 24th Annual Conference will take place in Glasgow from 20-22 October.

The theme for this year is "Dignity and autonomy in dementia". The conference will explore how recognising the human rights of people with dementia, their carers, partners and families is key to ensuring dignity and respect, as well as overcoming stigma. The role of peer support and dementia friendly communities will also be addressed.

Alzheimer Europe is currently inviting abstracts to be submitted for oral and poster presentations. If you are a researcher, or work with or care for a person with dementia and have a piece of research you would like to share, you can find out more and submit an abstract using the details below. This is a great opportunity to share your research, projects, initiatives and activities, and to exchange ideas with other participants.

Alzheimer Scotland will be actively participating in the conference, and warmly welcomes the Alzheimer Europe 2014 conference to Scotland.

More info

To find out more and submit an abstract, visit www.alzheimer-europe.org



PUERTO RICO



29th Annual International Conference of ADI to take place in Puerto Rico



Alzheimer's Disease International (ADI) will hold its 29th Annual Conference in San Juan, Puerto Rico, from 1-4 May 2014. The event is being co-hosted by the Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico, which was set up in 1983 and provides community-based support services and educational programmes to improve the quality of life of people with dementia.

The conference will feature an international faculty of speakers, with key figures from countries including Australia, the UK, Hong Kong, Puerto Rico, Sweden, Japan and Canada. It has a 'local meets global' focus, and will bring together local and international participants with the aim of creating synergies that inspire new ideas to improve the lives of those living with dementia. More than 1,000 delegates from over 60 countries are expected to attend.

The programme will include a panel discussion exploring the topic: 'The impact of new technology: should you be informed of your risk of developing Alzheimer's disease?'. During this session, the panel will discuss questions including 'With new imaging techniques now making it possible to identify changes in the brain before symptoms occur, is it ethical to provide an early diagnosis to those who do not show clinical symptoms?'

More info

For more information on the conference, visit www.adi2014.org/home

NORWAY

Our friends in the North

The last edition of Dementia in Scotland included a story about the Mayor of the Norwegian town of Moss, Tage Pettersen, who travelled to Motherwell to learn more about their dementia friendly initiatives. Since returning to Norway, Mayor Pettersen has wasted no time in implementing dementia friendly measures like the ones he saw in the North Lanarkshire town. We caught up with Mr Pettersen to see how much closer Moss is to becoming Norway's first dementia friendly city.

'Since returning I have had the opportunity to speak about dementia in several cities in Norway. In December I talked to many local politicians during a seminar, and in February I spoke at a big conference in Molde for people working within the hospital profession. My goal is to spread the word about our project to as many cities and municipalities as possible, and to challenge other cities to become

dementia friendly too.

'So far we have educated staff working in about 30 stores in Moss city, and more want to join. Our two football clubs are planning a 'Football Café' when the

our two football clubs are planning a 'Football Café' when the Norwegian football season starts

Norwegian football season starts in a month or two. We are also speaking with some volunteers who want to establish a meeting point where people can come and talk about the "old days" in Moss.

'In February we started a project inviting people with dementia who live at home along with their partners on a once-a-week trip to a gallery or a café. This



Mayor Pettersen, second from right, photographed during his trip to Motherwell.

project is a partnership between the municipality and volunteers.

'A lot of positive things are happening in Moss. The people involved in all these projects are really enjoying what they are doing. Moss is closer to reaching its goal of becoming Norway's first dementia friendly city!'

Last letter from Ghana

Jan Killeen, International Development Adviser, Alzheimer's Disease International, reports on her experiences in Ghana following her return to Scotland in December.

After 30 years working in the dementia field in Scotland it was a challenging and fulfilling experience to see how I could use the knowledge and experience we have collectively gained to facilitate the organizational and professional development of Alzheimer's Ghana. The keys to taking the dementia movement forward here proved to have the same motivating force in Ghana, namely the importance of forming collaborations and bringing influential professionals and politicians together at a high profile conference. 'Dementia: meeting the challenge in 21st Century Ghana', held on 12 December, proved to be a catalyst for change. I was delighted that Esther Dey, Chairperson and Chief Executive Office of Alzheimer's Ghana (seen in the photograph) confirmed

that the conference, which celebrated the organisation's first anniversary, successfully met all its objectives – raising public awareness through coverage by Ghana National Television, attendance of over 40 national and local politicians and professionals, the engagement of new board members and volunteers and the launch of the Dementia Appeal Fund. Sadly, I had to leave for home before the event and regard it as great tribute to the hard work of the Board (all volunteers) that the conference proved to be a landmark.

I'm giving remote support to Alzheimer's Ghana on a weekly basis for the next few months and enjoy receiving progress reports. An exciting development is a partnership with the Theatre Department of the University of Winneba

GHANA



which has produced an awareness raising play on 'Living with Dementia' to be piloted in two rural villages.

More info

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Where next? Debating the future of dementia care

On 24 February Alzheimer Scotland held a high-profile public debate on the future of dementia care, chaired by Sally Magnusson. The debate extended beyond the walls of the Royal College of Surgeons onto Facebook and Twitter.

Alzheimer Scotland held its 'Where memories go' debate on 24 February at Surgeons' Hall in Edinburgh. The open debate was sponsored by TC Young Solicitors and hosted by journalist and broadcaster Sally Magnusson. It tackled a range of dementia-related issues and was structured around five themes:

- carer support challenges
- acute care challenges
- residential care and care at home challenges
- diagnosis and stigma
- research.

Sally Magnusson's book *Where Memories Go: why dementia changes everything* was published in January. It explores many of the challenges surrounding dementia, including how we face the social, medical, economic and moral challenges as a society. In the book Sally describes the personal impact on her family of her mother's worsening dementia.

The debate and panel discussion explored the challenges raised in the book and – most importantly – looked at what happens next in the fight against dementia. The panel was made up of dementia experts and key decision-makers and included representatives from the Scottish Government, NHS Scotland, social services, and the care and research communities.

The very first question of the night was 'Who is in charge of joining up health and care services?' Geoff Huggins highlighted the need to coordinate services and the real challenge of ensuring that existing services meet the needs of the individuals who rely on them. Henry Simmons responded by emphasising the importance of the Promoting Excellence framework: 'It will bring people closer together.'

The panel of experts

Geoff Huggins, Head of Mental Health, Scottish Government

Ron Culley, Chief Officer, Convention of Scottish Local Authorities

Malcolm Wright, Chief Executive, NHS Education for Scotland

Anna Fowlie, Chief Executive, Scottish Social Services Council

Ranald Mair, Chief Executive, Scottish Care

Dr Peter Connelly, Co-Chair, Scottish Dementia Research Consortium

Lesley Hurst, Partner, TC Young Solicitors

Henry Simmons, Chief Executive, Alzheimer Scotland

The issue of costs and budgets was raised throughout the evening. Many audience-members expressed their frustration at the belief that adequate funding has been lacking for many years. Henry Simmons expressed his view that the money that is currently being spent on dementia care – around £2.2 billion – should be used more wisely. Malcolm Wright added that 'Poor quality care is more expensive than good quality care.'

Sally Magnusson described a vision of care for people with dementia being supported at home for longer, with that care becoming more professional. She then asked the panel if this was actually possible. Ranald Mair was first to answer, saying 'It is practical. The problem is funding. We can't have great care for £350 an hour'. He explained that councils in Scotland purchase nursing home places for £580 per week, based on 24-hour, 7-day care, which equates to £345 an hour, adding, 'Expecting high quality [care] to be

delivered at the level that we are currently at is completely unrealistic. We need to invest in the workforce. We need to value the people doing the leg work. This includes rewards and a career structure. We need to have care as an attractive career.'

Geoff Huggins added that Japan – which has one of the oldest populations in the world – has recently introduced a VAT rise in part to pay for older age care including dementia. Many members of the audience agreed they would be willing to pay higher taxes for better care, but Mr Huggins was quick to remind them that dementia isn't the only issue in our country and if we were to raise VAT and tax to support dementia care, there would be





Numerous Tweets were broadcast during the debate (a small selection have been included below). Many questions to the panel were also submitted by Twitter before the debate.

D @mummyberg

@future_chris Staff retention issues affect the cared for and their families. Consistency is key. #alzscotWMG

Ann Y @EildonLass

@alzscot #alzscotWMG. Nailed it - value folk in the caring profession and make payment commensurate with job.

Kerry Cannon SSSC @KerrySSSC

HS: "very few people set out to do a bad job" ...enhanced skills essential for better care, ie Dementia Champions programme #alzscotWMG

Theresa Douglas @DouglasNes

#wherememoriesgo #alzscotWMG debate hears of difficulties for staff in challenging cuts in services for people who have dementia

Elaine Hunter @elaineahpmh

Alone, lost, confused, frightened & at time angry - some of the emotions described by @sallymag1 at the opening of the debate #alzscotWMG

See the debate

You can watch a video of the debate on Alzheimer Scotland's YouTube channel: www.youtube.com/AlzheimerScotland



Playlist for Life launches Dunfermline pilot project

The Carnegie Dunfermline Trust has awarded £10,000 to Playlist for Life, which uses personalised music playlists to enhance the wellbeing of people with dementia. This will fund a pilot project in Dunfermline enabling more people with dementia to enjoy the therapeutic benefits of music.

Playlist for Life was founded by Sally Magnusson in response to her personal experience of her late mother's dementia. The charity helps people living with dementia access personally meaningful music on iPods. Despite all the other difficulties associated with dementia, Sally's mother Mamie continued to respond to music until the very end.

During the pilot, Andy Lowndes, Playlist for Life trustee and trainer, will provide specialist training to staff from care homes and voluntary groups, as well as family carers. Dunfermline was selected as the size of the community provides a balanced cross-section of those affected by dementia, both within family homes and residential care.

Robin Watson, Chairman of the Carnegie Dunfermline Trust, commented: 'Sharing music that has personal meaning for an individual can help family members and others looking after someone at home or in residential care recover the closeness of a relationship.' Sally added: 'This generous assistance will enable us to develop a training programme that will bring the benefits of personally meaningful music to people with dementia in Dunfermline and also provide us with a model we can take elsewhere. We can't wait to get going.'

More info

Visit www.playlistforlife.org.uk

PLAYLIST FOR LIFE
CONNECTING MUSIC. PEOPLE AND MEMORIES

other requests for similar treatment.

Ranald Mair observed: 'The Scottish Government says that we have a surplus of nurses, not a shortage, a surplus. But it is hard to get them into the care industry.'

With time quickly running out, Sally Magnusson pushed the discussion onto legal issues, with the main topic being power of attorney. Lesley Hurst, a partner at TC Young Solicitors, spoke about the value of making plans early: 'Putting legal

last 10 years there have been no new treatments and antipsychotics are still risky.' He continued by emphasising the importance of funding and pressed decision-makers to make this happen.

After the event, Sally Magnusson explained: 'Tonight was about taking some of the issues that I drew attention to in my book – which came out of my experiences – and putting these to a panel of decision-makers, the people who

We can't have great care for £3.50 an hour. We need to invest in the workforce. We need to value the people doing the leg work.

documents in place means that when a crisis occurs the paperwork is already there.' Henry Simmons commented on the importance of making sure the correct powers are specified by the individual.

With time almost up, Sally Magnusson asked Dr Peter Connelly to summarise where we currently are in terms of dementia research. He replied: 'In the

actually have a responsibility to make care better. I was glad to be able to do that and I think it was a useful airing of the issues. I think it may be useful to have at least one further debate in which we try to put some of the same questions a few months further on and see whether any of the work talked about tonight has actually come to fruition.' ■

Improving care in acute hospitals: the journey so far

Ros Moore, the Chief Nursing Officer for the Scottish Government, describes the steps that have been taken to improve the care of people with dementia in acute hospitals.

In 2011, Alzheimer Scotland was commissioned by Ros Moore, the Chief Nursing Officer for the Scottish Government, to organise a series of listening events. She and her team wanted to hear from people with dementia and their carers about their experiences of being cared for in acute hospitals, and how they might improve them. These experiences varied – some were positive, but many people described care that fell far below an acceptable standard. Here Ros Moore describes the progress that has been made in improving care for people with dementia in acute hospitals, and ongoing plans to make sure this improvement continues. I started my career as a nurse working with older people in a general medical ward in the 1980s. This developed into a lifelong commitment to safeguarding the care of older people and ensuring they get the best deal they possibly can. It's been a mission of mine throughout my working life.



Several years ago the Scottish Government introduced new measures to improve standards of care for older people in hospitals. The start of the process was a commission in 2010 set up by Nicola Sturgeon, who was then Cabinet Secretary for Health. This looked at the changes we needed to make to benefit all older people being treated in acute hospitals – not just people with dementia. At the same time she instructed Healthcare Improvement Scotland to

independently review the care of older people in acute hospitals.

Around the same time Scotland's first Dementia Strategy was published, and this included a commitment to improving the care of people with dementia in general hospitals. I was asked to take the lead on this and was pleased and proud to do so. One of the first things we did was take part in a series of listening events in partnership with Alzheimer Scotland. These gave people with dementia and their carers the chance to share some of their experiences in areas where we might improve. The partnership with Alzheimer Scotland made a real difference to the process and enabled us to hear the voices of the people who had experienced poor standards of frontline care.

Some of the sessions were very difficult to hear. Similar themes kept coming up and these reinforced our commitment to really find a way forward. I'm very keen that those people who shared their experiences know that we did listen. While we know things aren't always as good as they might be, the commitment to addressing them remains as strong as ever.

Those voices fed into the strategy we followed and led to detailed discussions about the need to educate staff, and to have specialists in hospitals who could really advocate for people with dementia. One of the first things we did was to ensure that staff in all parts of



hospitals had some understanding of the needs of a person with dementia. We introduced Promoting Excellence, which put a benchmark in place for the level of education, training and development we expect people to have.

The next stage was to invest in the development of the Dementia Champions programme, and that's been incredibly successful. The champions are working in health and social care settings (mainly health at the moment) and we have over 400 in place. They are a real critical mass of people with skills from a huge range of backgrounds including allied health professionals (such as physiotherapists and dietitians) as well as nurses. For many Dementia Champions, direct care for people with dementia is not a core part of their job, but they are committed to making improvements, and they have already made a difference.

I'd never underestimate how challenging it is to achieve large-scale change, even with the best will in the world. The first year was about capacity building through the Dementia Champions, and also the Alzheimer Scotland Dementia Nurses. The Dementia Nurses have been through a very challenging educational process and we now have one in every board, which is a great asset. We are about to evaluate the positive changes they have made. You've only got to look at the recent review of their work (see page 27) to see the range of things they are doing and how much they are making a difference.



Left: Newly qualified NHS Lothian Dementia Champions photographed with Colin MacDonald, Alzheimer Scotland Dementia Nurse Consultant (left) and Jenny Reid, AHP Consultant (right).

Another important factor has been the introduction of the OPAH inspections (Older People in Acute Hospitals). We made sure that the dementia standards were covered by inspectors and I now receive a steady stream of information around what's going well and what we need to change, which I can then

practice actions into the DNA of the NHS in Scotland. We want to make sure this work is at top of each board's agenda. I call it 'embedding it in the system' and believe it's the other key step that's necessary to really see services transformed. Carers are immensely important in achieving this and we are currently contributing to proposed legislation to further support carers and young carers.

Now we've increased frontline capacity through the champions and nurses, the next step will be to embed best practice into the DNA of the NHS in Scotland.

feed back into the ongoing strategy for further improvement. So far 24 acute care wards have been inspected covering 13 out of the 14 health boards, and the process is ongoing.

One of the outcomes of the inspections has been a greater investment in educating people around cognitive impairment. This is because we recognised that skills needed to be developed in that area. On a more localised basis, if the inspections show examples of attitudes or language that seem inappropriate then we will ask the Alzheimer Scotland Dementia Nurse to work with that unit to promote improvement. There is still a lot to do, but the inspections seem to be indicating that things are improving.

Now we've increased frontline capacity through the champions and nurses, the next step will be to embed these best

Working in partnership with carers is a key part of both the Dementia Champions and Dementia Nurses programme. We are also in the process of rolling out 10 key actions that each health board will be required to meet. One of these actions is that boards must demonstrate that they are working as equal partners with families, friends and carers. This is clearly set out as an expectation, and absolutely not an optional add-on.

The 10 key actions are included in the government's second dementia strategy, which was launched in June 2013. This shows just how committed Scottish government is to carry on the good work of the first strategy. One of the second strategy's commitments is to 'extend the work on quality of care in general hospitals to other hospitals and NHS settings' and my department is specifically responsible for that.

As part of my work I visit every health board in Scotland at least once a year to see first-hand how the work on dementia is going and how it's making a difference. What I'm hearing is that the investment we've made in capacity and capability has really put dementia right on everyone's agenda. There's not a ward I go to where there isn't something specifically relating to dementia care: whether it's a notice on the notice board, information or a special package of care being provided. The physical environments have also changed dramatically in the last two years to be more appropriate for people with dementia. In general medical and surgical wards these adaptations are absolutely in your face, and that wasn't the case four years ago. During my visits I always talk to the senior charge nurse about the impact of the changes and make sure they really keep dementia care at the centre of their strategic planning.

We're currently looking to appoint a specific improvement lead in dementia care in hospitals. This will be a national lead and we're at the appointment phase at the moment.

A wise man called Muir Grey once said that 'Transformation is not a destination like Birmingham or Bristol, waiting for our arrival – it is something we have to create'. I think we have made great strides in the last couple of years but we know it's a long journey, and my personal commitment remains undimmed. My thanks again to those people who, through their stories, set me going in the right direction. ■

Dementia Awareness Week Conference 2014: *Innovation, Research and Technology in Dementia*

Alzheimer Scotland is delighted to announce that our Dementia Awareness Week Conference will take place on Friday 6 June 2014 at the Crowne Plaza Hotel, Glasgow. This conference will be a must-attend event for anyone with a professional or personal interest in dementia – particularly those involved in research or developing assistive technologies.

This year's theme, Innovation, Research and Technology in Dementia, will explore:

- assistive technologies and the ethics of technology in dementia care
- the latest dementia research
- innovations in policy and practice
- looking to the future – locally, nationally and internationally.

Confirmed speakers include:

- Prof. Frank Gunn-Moore (Professor of Molecular Neurobiology – University of St Andrews)
- Scott Downie (Memory Box) and Caroline Howes (Memory Lane Games)

- the Missing Persons Bureau
- the Dementia Dog project.

There are three exciting new developments for this year's event.

The first is a **live debate** on a hot topic in dementia care and support. Participants will be asked to listen to different perspectives on this issue before being asked to vote on their preferred option.

The second is the **Tech Zone**, which will form part of our exhibition area. Here conference attendees will be able to see and try out a selection of the latest dementia-related apps (and other technologies).

Last, but by no means least is our **"dragons den" style competition** to find the next big (or small) idea that could transform care and/or support for people with dementia and their families. The winner will receive £15,000 to help turn their idea into a reality. We are looking for innovative

ideas about dementia. New ideas that offer practical solutions to the everyday problems faced by people with dementia, their carers, partners and families. We are especially keen to see submissions relating to innovative uses of technology.

Competition

To find out more about our dragons den style event, please email Mark Leiper: mleiper@alzscot.org



Jan's on the crest of a wave

Alzheimer Scotland Regional Manager Jan Johnston is currently training to compete in this year's Clipper Round the World Yacht Race. As part of Team Garmin, Jan and her crew can expect to face high seas, gale force winds and whatever other challenges the ocean decides to throw at them; all to raise funds for our Dementia Dogs project.

60-year-old Jan has had to go through four levels of training over the last two years to become a member of Team

Jan and her crew can expect to face high seas and gale force winds on their 5,500 mile journey

Garmin. She will be part of their crew on Stage 7 of the race – sailing from San Francisco, through the Panama Canal and finishing in New York. This stage will see

her and her team travel 5,500 nautical miles and she hopes to raise £1 for every mile travelled.

'I went to night school in winter 2012 and gained my Yachtmaster theory certificate, then completed my skipper ticket in Autumn of 13. I'm doing this race as a very personal challenge but also to raise as much money as I can for Alzheimer Scotland and the Dementia Dog project.'

Jan's own dog, Jarrah, takes part in the Therapet programme, whose aim is to promote health, hope and healing by connecting people with specially trained, certified and loveable companion animals. The Dementia Dogs project (featured on pages 6-7) is adapting the Therapet model specifically to train dogs to support people with dementia.

Sponsor Jan

To sponsor Jan on her maritime adventure, please visit her **Just Giving** page: www.justgiving.com/SailorJan



Jan and Jarrah

Dementia Awareness Week Conference, Friday 6 June 2014: **booking form**



Please complete one form per person attending and return it to us by Friday 23 May 2014.

Post your completed form to:

Laura Gallagher, Alzheimer Scotland,
81 Oxford Street, Glasgow, G5 9EP,
lgallagher@alzscot.org, 0141 410 1072

1. Name and address details

Title (Dr/Ms/Mrs/Mr/other):

Name:

Job title (optional):

Organisation (optional):

Address:

Postcode:

Telephone:

Email:

2. Registration fee

Please tick the registration fee that applies to you. Early bird rates are available until **Tuesday 13 May 2014**.

Member (early bird): £65

Non-member (early bird): £95

Member (full fee): £85

Non-member (full fee): £115

3. Payment method (please tick as appropriate):

Cheque (made payable to Alzheimer Scotland)

Please send me an invoice (this option is only available for bookings made prior to Monday 5 May)

Credit card

Invoice/cardholder name and address (if different):

Title (Dr/Ms/Mrs/Mr/other):

Name:

Address:

Postcode:

Card number:

Expiry date: Card security code:

Signature:

4. Special requirements

I have special requirements (dietary/access/other):

5. Data protection

Please tick if you do not wish to receive further information about the organisation.

6. Terms and conditions

Bookings will be acknowledged. Refunds (minus an administration fee) will be given for cancellations made before the closing date. The organisation retains the right to make any necessary changes to the programme.

Booking online is quicker and saves Alzheimer Scotland money. Please book online if you can.

Book online at www.alzscot.org.uk/daw2014

“They say that opposites attract”

Dementia in Scotland talks to husband and wife Henry and Anne Rankin about their experiences of dementia following Henry's diagnosis in 2011.

HENRY

After telling my GP repeatedly that I had memory problems I was eventually referred to a memory clinic. I didn't have a clue what this was, and if I'd known I would see a psychologist I doubt I'd have agreed to go.

The clinic was quite a shocking experience. Anne and my daughter Kirsty were told to wait in the waiting room. The psychologist spoke to me for an hour, getting me to do all sorts of tests, as well as asking me lots of questions. The appointment ended with her telling me without any warning: 'What you have is vascular dementia'. I was told to come back in six months.

I walked straight past Anne and Kirsty and out of the building. I burst into tears. They came and found me and I said 'I've been told I only have six

months to live'. The whole experience was so blunt and confusing that I had been left with the impression I was terminally ill.

At that time I didn't know what vascular dementia was, and I started looking for answers on the internet. There was a lot of information, but one of the words I spotted was that it was terminal, and I couldn't get that out of my head. I think the word 'terminal' should be removed from descriptions of dementia.

For the first month after I was diagnosed I didn't want to go out and get the papers. I was frightened of bumping into a friend in case I couldn't remember their name. Dementia has changed things. I do still go out alone but not as often as I used to. On Friday nights I go to the bowling club and that's fine because I'm walked there and back, but I wouldn't go on my own.

We've got a whiteboard at home which is great. It has things on it like Anne's shifts. I normally ask what the plans are for the following day the night before so I know what I'm planning for.

The hardest part of coming to terms with dementia for me was telling friends about it. I used to be president of the bowling club and I had to tell the directors there about my dementia. In fact it turned out to be a great relief because they didn't judge me on the basis of my illness, just on what I have done for the club. To be honest I must be unique as the people I know don't treat me any differently from anyone else.

The biggest impact has been on the children. They found it hard to accept I had dementia. Maybe it was a fear of what it might involve.

The word dementia doesn't scare me now, as I know what it is. You've got to be positive. At the Scottish Dementia Working Group (SDWG) there's a lot of laughter. You've got to have humour.

I went to a conference and someone sitting behind me talked about people suffering from dementia and I put my hand up and said 'That's not correct'. A carer may suffer - they're doing more for their partner and they're the person who it has a really big impact on. The spouse or carer who



is embroiled in things they shouldn't be doing. It's them who suffer.

After the first SDWG meeting I said to Anne 'I'm not going back' but she replied 'Yes you are!'. By the third meeting I felt confident enough to speak and get my point across.

One of the things I've most enjoyed is getting to grips with new technology through the SDWG. We used Skype at the meeting in Dundee recently. What a difference it made. We were able to talk remotely to group members who couldn't be at the meeting.

It's absolute nonsense that someone with dementia can't learn new things. I admit that sometimes I'm cautious about new technology, and when I first saw the tablet that we use Skype on I was frightened and didn't want to make a fool of myself. But I tried it and it was fantastic. Learning something new is a challenge to me and maybe something I haven't had for a while is a challenge. Now I'm doing everything myself. That's the thing I've really enjoyed this year. ■

Scottish Dementia Working Group

The Scottish Dementia Working Group (SDWG) is a national campaigning group, run by people with dementia. It is the independent voice of people with dementia within Alzheimer Scotland. The Working Group campaigns to improve services for people with dementia and to improve attitudes towards people with dementia. Membership is open to people with dementia. To find out more visit www.sdwg.org.uk or phone 0141 418 3939.



ANNE

Henry had memory problems before being diagnosed and complained about them each time he was at the doctors. The GP just said 'You're too young to have anything wrong with you'.

the matter with Henry before he was diagnosed, but I didn't know how to get help. He was in a very dark place following his diagnosis. The kids and I were all worried he was suicidal. The help we got from Tracy and Michelle was the best thing that ever happened to us.

Henry had memory problems and complained about them each time he was at the doctors. The GP just said 'You're too young to have anything wrong with you'.

He was worried sick the first few weeks after he was handed the diagnosis. The turning point came when we made contact with East Renfrewshire Carers Centre, where we met Tracy Gilmour and Michelle Shaw. They were incredibly supportive and helpful and Henry started to feel more positive for the first time. Tracy and Michelle were working on a project called Facing Dementia Together at the time.

I'm a nurse and I had my suspicions about what was

I kept very much to myself at first as I had to get my head round it before I talked to anyone else, like colleagues. When I did the people I told were very supportive. I used to be full time working four 12-hour shifts a week. After Henry's diagnosis I dropped a shift and have since dropped a second, so I'm now down to 24 hours a week. Financially, that's had an impact.

There are times when I don't really notice Henry's dementia. Other times we can have the same conversation three or

four times, but we've learned to laugh a lot, as you can gather, and that's a great help. I take a pragmatic approach. We make the most of good days and take every opportunity we can to enjoy life.

Henry had a stroke in early January following his diagnosis and for 72 hours afterwards he didn't recognise me or the kids. I felt really sorry for them as we all got an insight into what Henry's dementia could be like in the future.

There are certain things we can't do any more like eating out or going to places Henry doesn't know unless someone else is with him. He used to be

and I said 'Stay there', but he decided to make his own way home and set off towards East Kilbride by mistake. Now we've both got an app on our phones and we can use this to see where the other one is.

There's no point thinking about the dementia. You just put it to the back of your mind. There are times when it comes into your mind if you don't fight it. I always look at the positives. Humour is very important for us and always has been.

My view is that if I can help people to have a better diagnosis, or help improve services, then I'm happy talking about dementia. I just want things to be better for the people coming after us.

No one 'suffers' from dementia and that's one word I hate. I'm not saying it's always easy. There are times when I sit at the back door and have a cry when things are a bit difficult. But if you have a good support network like our children, even just to say 'I've had a bad day', it really helps. As long as you've got each other and can lean on each other you're OK.

Tracy and Michelle encouraged Henry to join the SDWG. It was exactly what he needed. To be in company and to be able to help other people. He needed a goal and I felt this was the best place to get one. It's been great for him. ■

Our invaluable volunteers

Alzheimer Scotland's work is supported by over 650 volunteers who donate their time and expertise to support people with dementia all across Scotland. Our volunteers contribute in a huge variety of ways, and in this regular column we will be focusing on some of the amazing work they do.

Friendship through song

Susan Rendell is one of our Volunteer Coordinators based in Glasgow. It is her job to recruit new volunteers, train them, and then assign them to the most suitable service based on their skills. One of these is the Forget-me-Not service, which offers emotional support to people who have dementia by visiting them in the care home or hospital they are living in. Once the volunteers start work, the Forget-me-Not Service team is available for support and help for the volunteer throughout their placement. Susan explains the vital role volunteers play:

'Volunteers can be found at every level in our organisation. From admin, to answering the phones and befriending. I don't think people realise just how important a couple of hours of their time can be to someone else.'

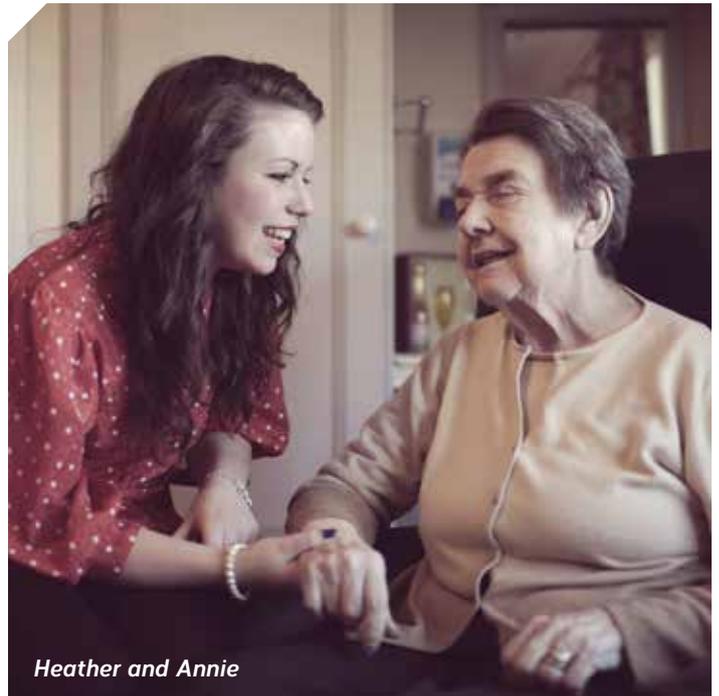
Heather Young has been a volunteer for the Forget-me-Not service at Alzheimer Scotland for a year and a half. She currently befriends two people living with dementia and spends quality time with each of them, every week.

Originally from the Isle of Lewis, Heather has lived in Glasgow for many years. Several years ago, her great aunt, who lives on Lewis, was diagnosed with dementia. Heather was keen to understand more about the condition, so she contacted Alzheimer Scotland to learn more about living with dementia.

'I got in touch with Susan Rendell at Alzheimer Scotland to see if I could start volunteering. I wasn't able to spend the time with my own family so I wanted to help someone else's family who were looking for some extra support. I really wanted to understand it from someone else's perspective.'

'Annie and I both speak Gaelic, a different sort of Gaelic, but I am still able to sing Gaelic with her. She finds a lot of comfort in Gaelic and when we first met I started off by singing a Gaelic lullaby to her. Now we sing lots of Gaelic songs together. So even though she might not be able to place me by name, there is a real emotional relationship between us and I'm certain she knows our friendship. Annie has learned a couple of Gaelic songs from me and I have learned a few from her too, which is really quite amazing.'

Annie's parents were from Islay and I'm from Lewis so we both speak Gaelic. She finds a lot of comfort in Gaelic. I started off by singing a lullaby to her. Now we sing lots of Gaelic songs together.



Heather and Annie

'I think Annie has got a lot from our friendship. She laughs, she smiles, and every time when I leave her I always ask her to give me her biggest smile then ask her to keep it there for me. We just have so much fun together. She is one of my best friends and I tell her that all the time.'

'If I was to speak to someone who was thinking of volunteering I would say that it will definitely change their life for the better. It will open their eyes to empathy, to relationships and how to be in relationships with other people - whether it is your family, your friends, or even complete strangers. It will teach them a lot about themselves. Volunteering with people who are living with dementia opens people up to new possibilities, to playfulness and to friendships that you will treasure.'

Susan adds 'This example of our volunteers going beyond their call of duty is not a rare occurrence and again exemplifies just how much they mean to Alzheimer Scotland.'

Support Heather

Heather will be running the Edinburgh Marathon this year to raise money for Alzheimer Scotland's befriending service. To sponsor her, please visit: www.justgiving.com/luckyduck

Using football to 'Remember Well'

Norrie Gallagher, Volunteer Co-ordinator for the Remember Well project in Motherwell, talks about the success of the project and the key role played by the volunteers who support it.

Remember Well is a football-focused reminiscence project that works with people with dementia, using football as a trigger to stimulate memories. We mainly work in groups, although there is some one-to-one work too. Many people who come along say that taking part improves their self-confidence and their mood – and of course it's about having fun too!

The group meets every week which really enhances the experience for the participants and enables us to keep up the momentum of working with them. Those involved say it gives them something to look forward to, as well as something new to talk about with family and friends. While the participants are with us their carers have an opportunity for some respite too.

Remember Well is a partnership project involving NHS Lanarkshire, North Lanarkshire Council, Alzheimer Scotland and Motherwell Football Club. It's funded by Comic Relief. However, the project couldn't operate without the invaluable

support from a wide range of volunteers. They're involved in everything from helping to facilitate groups, to preparing materials to make the meetings relevant and interesting. Other volunteers help out in different ways, like providing transport or offering individual support during group sessions if it's needed. We've also had help compiling stories for memory books (another project we are working on). One volunteer takes a lot of photos of the work we do, as well as filming it. An interesting development is that we now have a volunteer development group where the core band of volunteers are sharing their experience and commitment to look at ways of developing the project and improving the service we provide.



Former professional footballers, Joe Wark (Motherwell) and Billy Gray (Morton) have been Remember Well group members since the project first started.

Working with Fir Park Football Memories group as a volunteer has been an incredibly rewarding part of my life, and I consider it as a great honour to have been involved with both the members and their partners during this time. I have become great friends with all of them and the strength and courage shown by them will always inspire me.

Pat McCann, volunteer



Their interaction with each other and the various volunteers seems to increase week by week which is very rewarding and encouraging.

Bill Steven, volunteer

Pat and Bill photographed at Motherwell FC's ground, Fir Park.

Ann Hill receives Outstanding Achievement Award 2013



At our staff and volunteer awards ceremony in November, we were delighted to announce that Ann Hill was the recipient of our Outstanding Achievement Award 2013. Ann was the organiser and driving force behind 'Stitching the Pitch', a truly remarkable fundraising event that involved thousands of people donating quilts to Alzheimer Scotland. Thanks to Ann's incredible motivation, we received enough quilts to cover the pitch at Hampden Park. The sight of them all laid out on the pitch was unforgettable, and the event was hugely successful in highlighting our work, as it attracted a lot of media coverage. The quilts are now being sold to raise funds for Alzheimer Scotland. Congratulations to Ann on a really remarkable achievement.

Nationwide Tinsel, Tea and Talk events bank over £43,000



Over 150 branches took part in the Bank of Scotland's Tinsel, Tea and Talk fundraiser at the end of last year, with staff and customers joining in festivities while learning more about dementia, our work and the Live Well campaign. Alzheimer Scotland staff managed to visit 50 of the branches where we provided more information to staff and customers about dementia and the services we offer. Thanks to the incredible generosity of everyone who participated, a staggering £43,000 was raised. Bank of Scotland announced that they will match this amount which means the £25,000 target has been well and truly beaten. We would like to thank Bank of Scotland, their staff and their customers for all their help and support.

Football Memories Project - Sports Dinner 2013



A fantastic night was had by all at the Football Memories Project Annual Sports Dinner at Scotland's National Stadium, Hampden, on 29 November. The evening was a great success kicking off with a drinks reception held in the Scottish Football Museum, followed by dinner in the Lomond Suite with guests entertained by some wonderful speakers including Gordon Smith. A few well-known faces including Asa Hartford, Billy Hunter, Peter Cormack, Kevin Drinkell, Chris Shevlane, Alex Rae and Rose Reilly came along to help support the project. A grand auction, silent auction and raffles throughout the night helped raise the very impressive sum of £15,950. Plans are already under way for this year's dinner - details to follow.

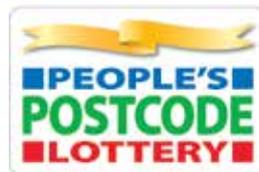
City Council staff boost quilt and Christmas card sales

In the run up to Christmas, two members of our fundraising team, Angie and Eirlys, went along to Edinburgh City HQ to sell quilts and Christmas cards. Over 80 quilts were sold and the final total raised was an impressive £1,295.05. The girls did so well that they are considering returning later in the year for another sale. We would like to thank Edinburgh City Council for their generosity in letting us fundraise from their headquarters, and congratulations to Angie and Eirlys for a great day's work!



People's Postcode Lottery vote success nets £10,000

Last year we took part in the People's Postcode Lottery Vote together with our sister charity, Alzheimer's Society. We were up against eight other UK charities, so we faced some fierce competition. The results were announced in November and we were delighted to come 5th! Every vote really did count, as the charity in 6th place only had 20 votes fewer than we did! We would like to take this chance to thank all our supporters. We could not have done it without you. Not only have we won a significant amount of money, but we have also recruited more followers on our social media channels and can raise awareness to more people about the fantastic work we do. The prize money will be going towards funding for our Dementia Advisor programme.



TSB's fundraising teams top £100K for Alzheimer Scotland



Alzheimer Scotland would like to say a huge thank you to staff and colleagues at TSB for their phenomenal support throughout 2013. The Scotland Charity Committee organised everything from sponsored walks to gala nights and bake sales, which with matched giving helped raise £100,000 as part of our Charity of the Year partnership. One of the many successful events was the TSB Gala Dinner, held in the Marriott Hotel, Dyce, on 30 November. 150 guests enjoyed a drinks reception, 3 course dinner, auction and ceilidh, raising £7,000 for Alzheimer Scotland and the Live Well Campaign, as well as supporting carers of people with dementia. This figure was matched by the bank, bringing the total to a staggering £14,000!

More info

You can view and buy a selection of beautiful, unique quilts by visiting:
www.alzscot.org/shop/quilts

Braving the Antarctic for Alzheimer's

In November last year, wife and working mum Audrey McIntosh became the first Scot to complete both the Antarctic Ice Marathon and the Antarctic 100km Ultramarathon, all within the space of three days. She ran in temperatures of up to -30°C to finish 13th out of 53 in the Ice Marathon and 3rd in the 100km ultra marathon – all to raise money for Alzheimer Scotland.



I decided on Antarctica because I was looking for a big running challenge. It had been a couple of years since I had done any charity work and as I usually got support from the same people, I decided that I really needed to give them something special to sponsor me for.

September 2012. This gave me just over a year to prepare myself for the event. When I told my husband that I was planning on running an ultramarathon in Antarctica he was quite confused. He said "You don't like the cold, you hate camping and it is miles away!"

our base camp at Union Glacier, in the deep south of the Antarctic circle. Not even the penguins go that far south!

The Ice Marathon took place on 20 November. We had to wear special gear to ensure we didn't injure ourselves in the harsh conditions. This included three layers as well as a wind-proof shell. We also had to keep our heads covered with a hat, goggles and face mask. Not to mention the double gloves. I also wore special trail running shoes which helped with the uneven ground.

The ultramarathon took place on 22 November and there were only six of us running. It was a 10km course that you completed ten times. After the first lap I was on my own for the remaining 90kms.

We started around 2pm in the afternoon and it took me over 17 hours of running alone to complete. However, I had no concept of time because at that time of year Antarctica has sunlight 24 hours-a-day.

Audrey managed to complete both the marathon and ultramarathon, becoming only the second British woman to do so. After the double marathons, the group of cold runners were stranded in Antarctica for 5 days because of poor flying conditions. However, the extra time didn't bother Audrey.

There was plenty of food and plenty to do. Antarctica is just so incredibly beautiful too and I knew that I probably would never see it again. I even went out for a two mile run on one of the days!

More info

Audrey is still accepting donations. If you wish to donate please visit www.justgiving.com/Audrey-McIntosh1

I chose to run for Alzheimer Scotland because it is a charity that is close to home. My uncle has dementia and my husband sadly lost two aunts to the illness.

I chose to run for Alzheimer Scotland because it is a charity that is close to home. My uncle has dementia and my husband sadly lost two aunts to the illness. I felt that this was a cause that would get me really motivated both physically and mentally.

I signed up for the Ice Marathon in

One of the most difficult parts of the whole adventure was getting to Antarctica in the first place. It took four flights and 31 hours to get to our rendezvous point in Punta Arenas, on the southern tip of Chile. We stayed there for a couple of days before we embarked on the final four-and-a-half hour flight to



Audrey receiving the award for the female winner of the 100km Ultra Marathon.



Alzheimer Scotland
@alzscot

TWEETS 4,247 FOLLOWING 2,808 FOLLOWERS 7,149



Tweets



Anne Buchanan – South East & Central (works part-time with Ruth McCabe) @annebuchanan16
Former Nurse Director for NHS. Loving the new job. Knew about AlzScot through my previous job and knew that it was where I wanted to work.



Karen Fraser - Highland, Western Isles & Orkney
@rosesblue
Privileged to be part of the regional growth of a charity. AlzScot provided a lot of help for my Granny. They are a wonderful organisation.



Gabrielle Colston - Grampian, Tayside & Shetland
@gabscolston
Previously AlzScot Dundee Service Manager for 15yrs. Daunting but exciting new challenge ahead. Looking forward to making a real change.



Jean Armitage - Argyll & Clyde @jean5724
Former Service Manager for Argyll & Bute since 94. I love being part of an organisation that puts people at the heart of everything.



Gerard McCoy - Ayrshire, Dumfries and Galloway
20+yrs experience in 3rd sector. Personal experience with dementia has taught me a lot. I want to make a positive contribution to my area.



Arlene Crockett – Glasgow, East Dunbartonshire & Lanarkshire
Been with AlzScot for 13 years. Previously a Service Manager, but enjoying my new role and the challenges it brings. Exciting times ahead.



Ruth McCabe – South East & Central
(works part-time with Anne Buchanan)
2014 plan - Increase membership, involvement and fundraising. Can't wait to use my skills and experience to help those living with dementia.

Meet Alzheimer Scotland's new deputy regional managers

Alzheimer Scotland has recently appointed seven deputy regional managers (DRMs) across Scotland. The new DRMs will enable us to link in even more closely with our local branches (run by volunteers) and our services, which are run by our staff with the support of volunteers.

In Scotland our population is spread far and wide across very different types of communities. We're determined to provide a voice for people with dementia, their families and carers, in every community, whether they're located in the densely populated Central Belt or the far-flung corners of the Highlands and Islands. Our new DRMs are already helping to strengthen those links.

In this article we introduce you to the DRMs with seven 'Twitterviews'. These bite-sized interviews are written in the style of a posting on the social media site Twitter, where the maximum length of a message is 140 characters. If you'd like to contact your local DRM, you can find their details on our website, www.alzscot.org.

Follow us!

To keep up to date with the latest news from Alzheimer Scotland on Twitter, visit twitter.com/alzscot and click on the 'Follow' button



Inverclyde Council funds link worker post for a further year

Inverclyde Council recently allocated £70,000 to support their local dementia strategy, Working towards a dementia friendly Inverclyde. Half of this will be used to fund the local Dementia Link Worker, ensuring she can continue her work for the next 12 months.

Jan Johnston, Alzheimer Scotland's Regional Manager for Argyll and Clyde, welcomed the pledge: 'I think it is great news that the Council has decided to recognise the Dementia Link worker with such a large investment. Susan Chandler, our current Dementia Link Worker, who works with colleagues in the Older Adults Community Mental Health Team, has a very important role and one which provides huge support for people in the area who have just been diagnosed, as well as for their families. It is our hope that other councils will follow suit and pledge more money for Link Workers in other areas. We are also hopeful that the role will be mainstreamed in the future.'

Alzheimer Scotland currently has 64 Dementia Link Workers in place across

Scotland. Most work as an integral part of local teams alongside health and social work staff. They are making a real impact in supporting people with dementia and their carers following diagnosis.

The link workers are playing a key role in delivering the Scottish Government's commitment to providing a year of post-diagnostic support. They use Alzheimer Scotland's 5 Pillar model of support to enable people with dementia, their families and carers to:

- understand and come to terms with their diagnosis and manage the symptoms
- meet other people with dementia and their partners and families
- keep community connections and make new ones
- plan for future decision-making
- plan for future care.



Inverclyde's multi-disciplinary dementia support team brings together health and social work staff with our local Alzheimer Scotland link worker. The result is dramatically improved support for people newly diagnosed with dementia.

Dementia awareness campaign launches in Edinburgh

A campaign to help people recognise the signs of dementia was launched in Edinburgh in January. Called 'Recognising the signs', it is a partnership between City of Edinburgh Council, NHS Lothian and Alzheimer Scotland.

The campaign is working to improve the quality of life for everyone living with dementia, as well as promoting awareness of the condition in their communities. It includes an advertising campaign highlighting the symptoms of dementia and teaching people how to recognise them. Information is also being circulated on the support available to those concerned about dementia.

Several of Alzheimer Scotland's link workers were at the launch of Recognising the signs, which took place on 28 January. They work in partnership with people who have been diagnosed with dementia – as well as their families and carers – to provide advice and support. Our national

network of link workers plays a key role in delivering the Scottish Government's commitment to a year of post-diagnostic support for people with dementia.

Speaking at the launch Helen Hay, Alzheimer Scotland's regional manager for South East & Central, said: 'Getting a timely diagnosis is hugely important for people with dementia and for those closest to them. It opens up access to information, advice and support; all of which are vital in planning for the future. This campaign is a fantastic opportunity to improve support for people in the early stages of their dementia journey and to make the public more aware of the impact of dementia and the many ways we can all help those affected by the illness.'



Practitioners team up to share expertise and improve dementia care

The Practice Collaborative is a group of professionals whose roles involve caring for or supporting people with dementia and their families. It is facilitated by Alzheimer Scotland's Centre for Policy and Practice at the University of the West of Scotland.

Members of the Practice Collaborative come together to share their expertise, help spread best practice, and carry out research to inform dementia care. It was set up last summer and is actively seeking additional members (see below for details of how to get in touch). Barbara Sharp, Alzheimer Scotland Research Fellow, is the coordinator of the Practice Collaborative.

In August the Collaborative held a development day to enable members (and potential members) to meet each other face-to-face, and to build their confidence as a group. During the day participants drew up plans for research topics they would like to take forward. Barbara Sharp explains:



as the conversation develops, giving a visual record of the discussion. Our Ketso workshop was great fun and an excellent way of gathering and categorising ideas.

Ketso looks like a giant fuzzy felt, but it's a really useful planning tool and ensures everyone has a voice.

'One of the main goals of the day was to break the ice and get everyone feeling comfortable working with each other, as well as confident to contribute ideas. By the end of the day we hoped to have a clear sense of the Collaborative's future direction, along with an agenda of action points to take forward afterwards. This included encouraging participants to identify partners to collaborate with and generate ideas for research opportunities in their field.'

'The first part of the day used Ketso to enable groups of participants to gather ideas and see how these fitted together. Ketso means 'action' in Lesotho, where it was invented. It provides a structured way of running a workshop where participants write their ideas on different coloured reusable leaves, then arrange these on a felt mat. It sounds like a strange idea until you try it, but it's a really useful planning tool and ensures everyone has a voice. The leaves can be moved and rearranged

'During the afternoon we held a workshop on carrying out research and writing up research results for publication. This was facilitated by Dr Peter Connolly and Emma Law of the Scottish Dementia Clinical Research Network. It was an opportunity for people to think about some of the practice processes they would need to use to develop the research ideas they had brainstormed in the morning.'

Members of the Practice Collaborative are currently engaged in projects around dementia and design; shared learning with families; dementia and smoking risk reduction; a bladder and bowel management project, and the development of 'master class' sessions.

More info

For more information about the Practice Collaborative, including details of how to become a member, please email Barbara Sharp: barbara.sharp@uws.ac.uk

QMU students complete placement



Chris Cousins and Mairi Ferrier, who are currently studying for a degree in occupational therapy, recently completed an eight-week practice placement at Alzheimer Scotland's Fife Dementia Resource Centre.

As part of their placement, the students from Queen Margaret University (QMU), shadowed Jane Maskelyne, one of Alzheimer Scotland's Dementia Advisors for Fife. Chris explains: 'We were able to go out with Jane and experience what a Dementia Advisor actually does. I also got the chance to visit a service user and do a bit a work with them on my own.'

Mairi added: 'We were involved a lot in group work as well. There are a lot of different groups that are run from the resource centre. It has been really helpful in showing us the positive side of living with dementia. There is such a great atmosphere within these groups, and great banter too.'

Jane Maskelyne explained: 'Having allied health professionals (AHPs) including occupational therapists on placement with Alzheimer Scotland offers opportunities for all concerned. It helps our staff to understand the roles of AHPs better, while the service benefits from the knowledge, experience and ideas the students bring. It also gives people with dementia greater awareness of the role of AHPs.'

'The people who use our services very much enjoyed and benefited from Chris and Mairi's input, whether on a one-to-one basis or in a therapeutic activity group. Mairi and Chris were both extremely hard-working and proactive in their learning. As part of their placement they researched, wrote and presented a two hour workshop on 'Activities and dementia' to volunteers.'

Mairi added: 'This experience has really inspired us both to pursue a career in dementia care, so we will see what happens!'

A year of progress for early onset dementia research

Living with early onset dementia can be tough, and you soon find out who your friends are, as Jenny explains: "You lose friends, even friends that I saw on my own. I don't see them now. They've just not bothered to get back in touch."

Early onset dementia is the term used to describe people who receive a diagnosis before the age of 65. An estimated 3,200 people with early onset dementia live in Scotland. There is a growing awareness that early onset dementia can have a particularly devastating impact on people's lives.

Alzheimer Scotland's Edinburgh and West Lothian Services has been pioneering support for people with early onset dementia since the 1990s. In autumn 2012, the service and the University of Edinburgh's School of Health in Social Science formed a five-year research partnership to help identify ways in which families living with early onset dementia can be better supported.

Alan Midwinter, service manager, explains: 'Working in partnership with the University of Edinburgh means our combined voice has more authority when we talk to those people who form and influence policy. We've got more impact

than if we worked individually.'

Edinburgh University and Alzheimer Scotland will be working together on a range of research projects, workshops and events to better understand families' experiences of living with early onset dementia and learn how services can be improved. The aim is to communicate this information to key policy-makers and service leaders to achieve meaningful and lasting change.

Lunch @ The Botanic

Last April, the partnership held an informal lunch at the Royal Botanic Gardens in Edinburgh, where families who use the service could meet Edinburgh University researchers, socialise with each other and find out more about their research ideas. Over 40 people attended.

Drama workshop

In May 2012 it organised a drama workshop so families could come together and share some of their experiences in a fun, friendly and informal way. This was led by Edinburgh-based theatre company Strange Theatre. They use participatory theatre to help people



communicate their experiences of ill-health and social exclusion. Afterwards Strange Theatre dramatised and filmed some of the scenarios described by participants (pictured).

Family interviews

During the summer and autumn of 2013 families and individuals who use the service were interviewed to find out more about their experiences. Early results are already highlighting some really important questions and identifying areas in need of further development.

More info

To find out more about the research partnership, please contact Dr Nicholas Jenkins at the School of Health in Social Science, University of Edinburgh: n.e.jenkins@ed.ac.uk

Making a difference every day

Alzheimer Scotland's legacy officer, Sarah Anderson, describes a chance encounter with a family during an event in December which gave a valuable insight into the importance of the work we do.

I was helping to sell cards and quilts at last year's Christmas Fair and had taken along some leaflets about Alzheimer Scotland's services. A woman in her twenties, with her grandfather on her arm, came to the stall. They had a look, smiled and chatted then moved along. Before she left the table, I noticed the girl pick up a Helpline card and quickly pop it in her pocket.

About five minutes later, a lady in her late forties walked past. She glanced at the literature then moved on. Five minutes after that, a lady in her seventies came over and looked at our wares. She picked up some cards and made a purchase. As I handed over her change,

she leant forward and quietly told me "We use your services, and we're very, very grateful for what you have done for us. My husband was diagnosed with dementia a few months ago. We are very glad to have your support."

I thanked her for the feedback, and reminded her about the other support we offer, including our Helpline. I showed her the Helpline cards and she immediately popped one into her purse. When I asked her how her husband was keeping she gestured to the girl with her grandfather and said "He's very well, thank you".

This chance encounter was particularly meaningful because 20 years ago I was that woman, only it was my Gran on my arm. My mum really struggled to come to terms with what was happening and we knew nothing of dementia or where the journey would take her. To see this family supported by our services, and

now supported by our literature and Helpline, reinforced just how important all of our work is, and how grateful and honoured I am to work for Alzheimer Scotland.

Many people, like me, who are based at National Office in Edinburgh don't spend a lot of time with service users. I wanted to share this experience so you all know just how appreciated your work is.'



We use your services, and we're very, very grateful for what you have done for us

New policy to protect older people who are victims of crime

Last August, the Crown Office and Procurator Fiscal Service (COPFS) launched a new policy to protect older people who are victims of crime. This provides guidance for prosecutors on how to deal with crimes where an older person is a victim or witness. The policy was launched by the Solicitor General for Scotland, Lesley Thomson QC.

Prosecutors regularly have to deal with cases of doorstep crime, for instance crimes involving financial scams or bogus workmen, often targeting vulnerable older people. In recognition of this, lead prosecutors have now been appointed across Scotland to lead on crimes committed against older people. All prosecutors have been instructed to take a robust approach to these types of crime, and the policy includes the following guidance:

- there is a strong presumption that a prosecution will go ahead where there is enough evidence

- cases won't be discontinued when they get to court unless there is a change in circumstances
- cases involving older victims and witnesses will be prioritised
- assumptions will be made about the capacity of a witness, and prosecutors won't discount a statement given by someone who has dementia because of their illness
- because it can often be a challenge obtaining and presenting evidence from witnesses who have dementia and other age-related illnesses, prosecutors will look at alternative ways of getting their evidence into court if they are unable to give it themselves
- all victims and witnesses over 60 will be referred to the Victim Information and Advice service. This will provide information about the case and explain what assistance is available to help them give evidence in court.

In February the lead prosecutors held a joint training session with officers from Trading Standards and Police Scotland

who specialise in this area of work. They discussed ways of improving the way doorstep crime is investigated and prosecuted. Jim Pearson, Deputy Director of Policy for Alzheimer Scotland, was able to take part in this training and spoke about practical measures that can help when taking statements from victims with dementia. Jim described how even simple steps, such as choosing the best time and place for taking the statement, can help obtain better information and minimise stress for victims.

Talking about the new policy, Catriona Dalrymple, Head of Policy Division at COPFS, said: 'We are very grateful to all those at Alzheimer Scotland who contributed their expertise when we were developing this policy. We believe it will be an important tool for improving our service to victims and witnesses.'

More info

The policy can be downloaded from the COPFS website: www.copfs.gov.uk

Interested in improving care services in Scotland? Visit The Hub.

The Care Inspectorate protects some of the most vulnerable people in Scotland by making sure care services are as good as they can be. It regulates care in care homes and care that is provided to people in their own homes – two areas that are often relevant to people with dementia.

The Hub is a new website from the Care Inspectorate with all sorts of information about ways of improving care services. It has a wide range of resources that will be useful for people who work in the care sector. Examples include a library of good practice guidance, and toolkits to support improvement.

If you're a member of the public there's useful information on The Hub for you too. For example, you can watch videos showing examples of organisations that are providing care in innovative and exciting ways. You may discover ideas that you can use yourself, or that you can ask a care home or care at home service to introduce.

The Hub is also looking for people who have experienced excellent care and would like to tell other people about it. You can be a member of the public, or represent an organisation that provides care.

More info

To find out more visit www.hub.careinspectorate.com



Do you claim Disability living allowance and have a DG, EH, TD or ML postcode?

A new benefit called Personal independence payment (PIP) is being introduced to replace Disability living allowance (DLA). PIP is being rolled out gradually and will replace DLA in some parts of Scotland before others. From January 2014, anyone claiming DLA who reports a change in their circumstances and who lives in postcodes beginning DG, EH, TD and ML will be told to claim PIP rather than DLA. You can find out more about PIP and see how you may be affected by visiting www.gov.uk/pip

Make sure medical staff have ‘key information’ about your care

The Key Information Summary (KIS) is a new system for summarising important information about a person’s medical history, and specific wishes they have made about their care. KIS information is stored in your GP electronic record. With your permission (granted beforehand during a discussion with your GP), medical staff working in NHS 24 and Out of Hours services can access your KIS if you need care when your GP surgery is closed.

Alzheimer Scotland believes that having a KIS can be very helpful for a person with dementia, as it can provide quick access to important information that they may not be able to pass on if they need medical treatment. It can also include information

about things like your preferred place of care, or any specific wishes or special instructions you have made.

How to get a Key Information Summary

If you think a KIS would be useful for you, you should **ask your GP to create one for you**. They will explain how it works, how it will be updated, and who will have access to it. Remember that having a KIS is optional and you don’t need to have one if you don’t want one.

More info

To find out more visit www.nhs24.com/Explained/MyInfoNHS24/WhatIsKIS



Mount Kilimanjaro fundraising challenge

Join us in Glasgow on 29 May to find out more about trekking Mount Kilimanjaro in 2015 to raise funds for Alzheimer Scotland. Follow in the footsteps of other intrepid fundraisers such as Dementia Nurse Consultants Anne Hutchinson and Sandra Shields who are currently training to trek the Great Wall of China. Sandra will be at the event, sharing her experiences of trekking in China.

Kilimanjaro trek



For more information about the Mount Kilimanjaro 2015 event contact Rachel Laming on 0141 946 0966 or rlaming@alzscot.org

Dementia Nurses review published

Alzheimer Scotland
Action on Dementia



Alzheimer Scotland Dementia Nurse network



Annual review 2013–14

Read about the work of our Dementia Nurse Network in a new review. Visit: www.alzscot.org/DNReview

Your unwanted jewellery can help us provide dementia services in your area

Send us your old or unwanted gold, silver, costume jewellery, even watches and we can turn these into £££s to help support people with dementia in your area. Broken and damaged items will help, so all of those odd earrings and snapped chains are a start. We will even accept your unwanted, old and new foreign and UK banknotes.

Donate today!

To order one of our Freepost recycling envelopes please email us at fundraising@alzscot.org or call us on 0131 243 1453.



Forget-me-not Ball

Sat 5 July 2014

Crowne Plaza Hotel, Glasgow



This year's Forget-me-not Ball will include big band sounds, jazz music, appearances from Tom Urie and some surprise River City cast members, as well as a drinks reception, three course meal (includes half bottle of wine per person) and a DJ for dancing till the wee small hours - all for just £45.

We are looking for help with prizes, sponsorship and pledges for the night and if you would like to get involved please contact Rachel Laming at rlaming@alzscot.org. The more help we get the bigger and better this night will be. All proceeds will help us create our new Resource Centre in Glasgow and give Kris Rodden, the ball's founder (inset), the legacy he truly deserves.



If you would like to come along on the night please go to our web page for more details: www.alzscot.org/FMNBALL

Inaugural Members' Advisory Forum

We are holding the first of our new Members' Advisory Forums on Wednesday 30 April in Edinburgh (venue to be confirmed).

The forum will enable Alzheimer Scotland members, stakeholders and advisors to explore and better understand current issues and to test new ideas. It will help us identify our priorities for the organisation nationally and regionally.

We had a wonderful response to an initial email invitation to members and the event quickly reached capacity. However, the invitation process highlighted that we do not have email addresses for everyone.

If you are happy to be contacted by email please send your email address details to Mark Leiper, Membership Officer (mleiper@alzscot.org). Mark can also be contacted by phone on 0131 514 0007 if you have any questions.

We will communicate details of the autumn forum, scheduled for 30 September (location to be confirmed) in the summer edition of Dementia in Scotland.

Booking for the event will be available from 1 August and once again we will email an invitation.



Programme for 30 April

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: End of life care: Ethics and rights around end of life care, and the implications of the end of the Liverpool Care Pathway.
11:15-11:30	Coffee & comfort break.
11:30-12:30	Second session: Innovations including the Dementia Dog project, the Dementia Circle initiative and wearable technology.
12:30-13:00	Sandwich lunch and networking.
13:00-14:00	Third session: Early diagnosis and awareness campaign.
14:00-14:15	Coffee & comfort break
14:15-15:00	Final session: Dementia friendly communities. Growth, expectation, impact, effectiveness.
15:00	Close.

FULLY BOOKED