

Dementia in Scotland



Winter 2015/16 – Issue 88



**FOR OUR TODAYS.
FOR OUR TOMORROWS.**

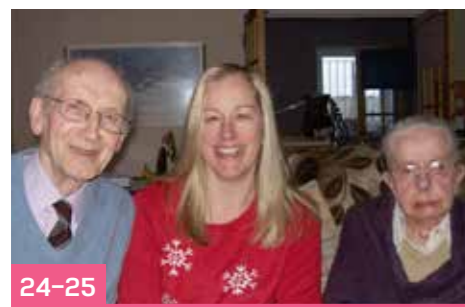
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Find out how our new Advanced Dementia Practice Model aims to ensure people with dementia have the best possible end of life.



Professor John Starr shares an update on recent research work at the Alzheimer Scotland Dementia Research Centre.



Relative Values. National Dementia Carers Action Network member Muriel Reid talks about the importance of knowing what you're willing and able to do when someone you love has dementia.



Discover how leaving a gift in your will can make a big difference to the lives of people with dementia in Scotland.



If you received a Home Money Box in your mailing turn to p33 to find out how you can use it to support us.



Were you at one of our Memory Walks this September? See if you can spot yourself in our photo gallery!

Welcome!

As we bring in the New Year, I would like to say a big thank you for all your support over the past 12 months. 2015 was incredibly busy for Alzheimer Scotland and in this new year we will have many more opportunities to champion change and improve policy and practice in Scotland on behalf of people with dementia, their carers, families and friends.

In this edition you will find a feature on our new Advanced Dementia Practice Model, which sets out an integrated and comprehensive approach to providing care and support for people with advanced dementia and experiencing end of life with dementia. From the point of diagnosis to the end of life, every person with dementia and their family deserves nothing less than the best care we have at our disposal. The Advanced Dementia Practice Model is the latest in a series of policy recommendations that we have made which have been readily accepted by the Scottish Government and implemented as part of the National Dementia Strategies. We are pleased that the Scottish Government has given the model a warm reception and have already agreed to pilot it in two local areas as part of the next National Dementia Strategy which will be launched this year.

Over the winter months we've helped the Scottish Government to gather your opinions on the progress of the current National Dementia Strategy and identify the gaps, opportunities and priorities in order to shape the direction of the next strategy. It's vital that people with dementia and their carers play a key role in the development of this latest strategy and Alzheimer Scotland is working hard to ensure your voices are heard.

As the number of people living with dementia in Scotland continues to rise it's more important than ever to plan for the future. In this edition we explain the importance of having a Power of Attorney in place as well as future care and estate planning. We've also provided information about how you can leave a legacy in your will helping us to ensure that nobody in Scotland has to face dementia alone, now and in the future. We also have articles on some of the incredible research and education work currently taking place in Scotland and in particular at two centres we contribute funding to – the Alzheimer Scotland Dementia Research Centre at The University of Edinburgh and the Alzheimer Scotland Centre for Policy & Practice at University of the West of Scotland.

I am afraid that this year we must brace ourselves for what looks like the most financially challenging period for Local Authorities and the National Health Service that we have seen for many years. We are already seeing huge pressures on services, and in some local areas policies from national strategies and commitments are not being implemented. Working with our supporters we have achieved some great policy outcomes over the last few years, the most notable being the guarantee that every person diagnosed with dementia will receive a minimum of one year's post diagnostic support. However even this flagship policy is not being fully delivered in every area and the gap between good policy and people's lived experience is simply too wide. It is taking too long to convert these policies into mainstream services and we need to speed up how quickly this happens. In this current economic

climate this means we must campaign even harder for the rights of people with dementia and their families and ensure that national promises on best practice models are delivered locally.

This year we will also have the opportunity to influence and speak with Scotland's political parties in the run up to the Holyrood elections in May. We will be asking them to continue to make dementia a priority and to commit to delivering the policies which we know will improve the lives of people living with dementia in Scotland. As a member or supporter of Alzheimer Scotland anything you can do to help encourage either the local or national prioritisation of dementia services and support is most welcome and appreciated. We cannot allow the excellent progress that has been made in recent years to be lost and if you want to get involved and help us in this please contact your local Policy and Engagement Manager to find out what is happening locally. You can find their contact details on p15.

Our members, supporters, volunteers and staff constitute a sizeable force for change and together we must use our collective strength and voice to not only protect the rights of people with dementia and their families but to improve them and ensure that their rights to choice, power, control and high quality care and support are fully upheld in every area in Scotland.

Henry Simmons
Chief Executive
Alzheimer Scotland



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Recognising dedication

Autumn was the season for awards ceremonies and we're delighted that Alzheimer Scotland staff and volunteers were recognised for their hard work across the country.



Dementia Advisors Polly Mark (left), Angi Inch (centre right), and Geraldine Ditta (right) accept Scottish Health Award from Dr Anne Hendry, National Clinical Lead for Integrated Care at the Joint Improvement Partnership Team.

Alzheimer Scotland Dementia Advisors win at the Scottish Health Awards

In November, our Dementia Advisor team won the award for Integrated Care for Older People at the Scottish Health Awards 2015.

The Scottish Health Awards is the most prestigious and recognised awards ceremony for healthcare professionals within Scotland, so this really was wonderful recognition of the amazing work they do across the country.

Polly Mark, Dementia Advisor for Glasgow South said: 'It was great for Alzheimer Scotland to be recognised at such a prestigious event in Scottish health. Making the shortlist in our category was an achievement in itself – but then to win, was truly unexpected. It was quite overwhelming and a wee bit emotional. It was a great honour to be there to accept the award on behalf of the Alzheimer Scotland family. The experience will stay with me for a very long time!'

Geraldine Ditta, who works as a Dementia Advisor in the Highlands commented: 'It was a magical evening. Having the opportunity to talk to such an audience about Alzheimer Scotland

and the work we do was tremendous. A treasured memory and I was only sorry more Dementia Advisors couldn't be there to experience it too. Next time!'

2015 saw us celebrate five years of Alzheimer Scotland's commitment to providing a specialist Dementia Advisor in almost every local authority area in Scotland. In those five years our Dementia Advisors have helped tens of thousands of people adapt to living with a dementia diagnosis. To date, we have dedicated £38 million of fundraised income to creating this indispensable safety net. If you would like to contribute to their fantastic work, visit www.alzscot.org/donate to make a donation now.

Two awards at Scotland's Dementia Awards 2015

In September, Alzheimer Scotland staff and volunteers won two awards at Scotland's Dementia Awards, which showcase creativity, innovation and dedication in the field of dementia services.

Volunteer Nancy McAdam, a longstanding member of the Scottish Dementia Working Group, was recognised with the event's Lifetime

Achievement Award. Nancy lives on her own, on a remote croft, 27 miles from Inverness. She was diagnosed with vascular dementia in 2003, at the age of 58. In 2004, Nancy and another person with dementia became the founder members of the Highland Dementia Working Group. Nancy is an incredibly active campaigner, speaking at and taking part in conferences and volunteering for local and national media opportunities on dementia issues.



Nancy McAdam is presented with her award by Alzheimer Scotland Chief Executive Henry Simmons



Alzheimer Scotland's Lanarkshire Mosque and Muslim Community Project win at Scotland's Dementia Awards.

Alzheimer Scotland's Lanarkshire Mosque and Muslim Community Project triumphed in the Best Dementia Friendly Community Initiative. The Lanarkshire project was developed following Motherwell becoming recognised as Scotland's first dementia-friendly town centre in 2012. Objectives of the project include raising awareness about dementia, improving communication between the Muslim community and service providers and reducing the stigma of the illness.

Scotland's Dementia Awards are a partnership between Alzheimer Scotland, NHS Education for Scotland, NHS Health Scotland and the Scottish Social Services Council.

Alzheimer Scotland staff and volunteers celebrated at our annual conference

Hard work, dedication and willingness to go the extra mile were celebrated at our awards ceremony during our Staff, Members' and Volunteers' conference in November.

The day was a great opportunity to review our activity in 2014/15, share

insights into different areas of work around the organisation and to catch up with friends and colleagues from around Scotland.

Influencing and Promoting Change Award – Anne McWhinnie (Dementia Friends Programme Manager)

Anne's work on Dementia Friends Scotland has touched many communities across Scotland, with over 16,000 people signing up to be a Dementia Friend.

Innovation in Dementia Practice Award – Julia MacKenzie (Dementia Link Worker)

Julia's approach to personal planning helps ensure that the person with dementia owns the plan and that it is shared closely with their family.

Volunteer/Branch Engagement/Dedication Award – Marina Gray (Volunteer)

Marina's commitment to 'living positively with dementia' is inspirational. Both Marina and her husband Ian, who lives with dementia, are extremely active in the Shetland dementia community.

Creative or Significant Fundraising Award – The Anderson Family

The Anderson Family organised an incredible Vintage Tractor Road Run and

Barn Dance which raised £10,700 for Alzheimer Scotland.

Lifetime Achievement Award – Bridie Donnelly (Service Manager – retired)

Over her 50 year career, Bridie Donnelly championed and supported many people within the health and social care systems. She has consistently inspired and motivated everyone around her.

Unsung Hero – Isabel Lappin (Receptionist)

Isabel is a very valued member of the Oxford Street Team in Glasgow. She always goes above and beyond what is expected and always does so with a smile on her face.

Length of Service Award – for staff who have been with the organisation for 15 years

Angela Smith, Rosemary Mearns, Elaine Morgan, Caroline Blake, Lesley Muirhead, Patricia Blyth, John Farquhar, Frances Kelly, Marion Budge, Carolyn Cormack, Ruth Montgomery, Catherine Mackay, Annie Kieran, Alyson Gravett, Teresa Stracynski, Elizabeth Darke, Julie Drummond, Fiona Dysart.

'Hard work, dedication and willingness to go the extra mile were celebrated at our awards ceremony.'



Alzheimer Scotland staff recognised for length of service.

New report provides roadmap to end of life care

Alzheimer Scotland was delighted to launch the Advanced Dementia Practice Model in November.

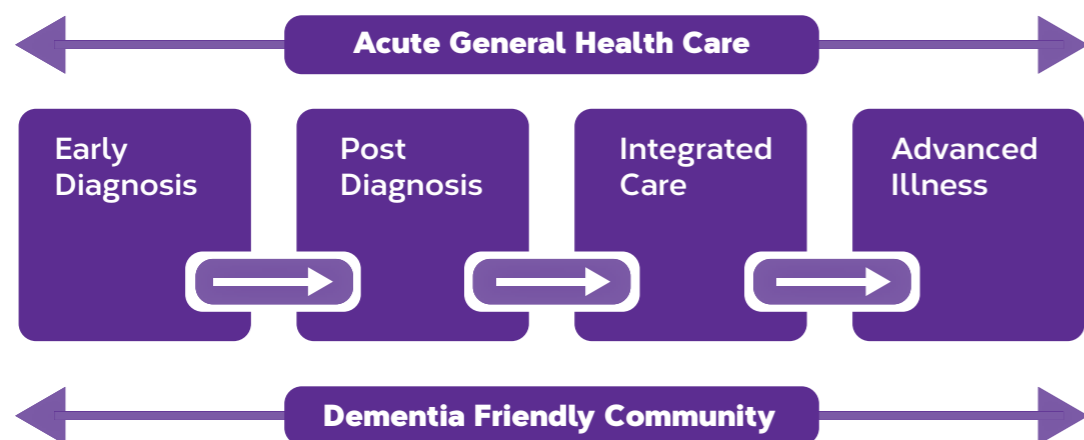
This comprehensive report took almost two years to create. It was developed through extensive consultation and information gathering processes, involving people with dementia, their family members and carers, professionals and partner organisations. We researched best practice and explored in depth the available evidence to understand and support people living with advanced dementia.

At the launch of the new Model, Alzheimer Scotland Chief Executive Henry Simmons said: "In Scotland, we have led the way in the development of a human rights based and person centred approach to dementia practice. Our transformational approach to diagnosis, post diagnostic support, integrated care, general health care and dementia friendly communities is recognised internationally as an example of best practice. We believe that the Advanced Dementia Practice Model provides us with the next step in this transformation. We are confident that the Advanced Dementia Practice Model offers the key to ensuring people with dementia have the best possible end of life."

This work is the culmination of a multifaceted, long-term programme of

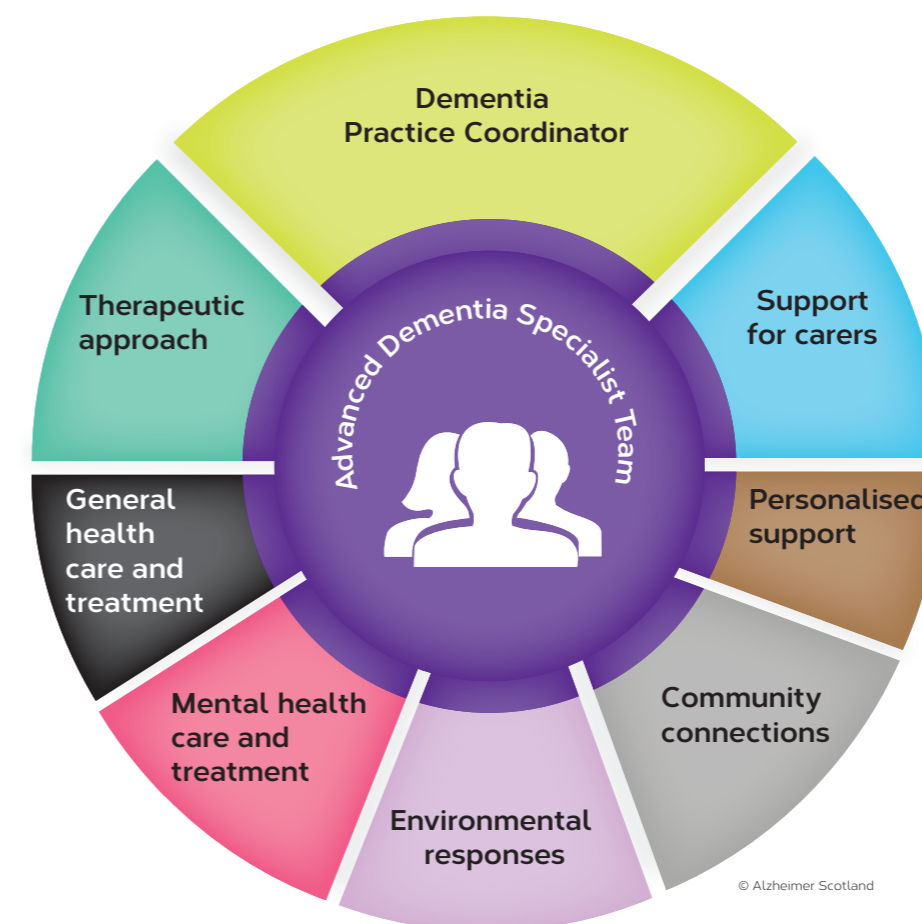
policy development within Alzheimer Scotland, which has prioritised six key areas crucial to transforming the lives of people living with dementia in Scotland:

- Acute and General Health Care:** We instigated, and continue to part fund, an Alzheimer Scotland Dementia Nurse Consultant in the territorial health boards, providing change leadership. We support the Scottish Government and the University of the West of Scotland to train dementia champions who work in hospitals across Scotland. In partnership with the Scottish Government and the NHS we developed the '10 Care Actions' detailing the key changes needed in acute care for people with dementia. And we continue to work with NHS Education Scotland and the Scottish Social Services Council to implement the Promoting Excellence Framework of knowledge and skills for professionals working with people living with dementia.
- Dementia Friendly Communities:** We have been at the forefront of developing dementia friendly communities across Scotland, including innovative work with
- different Black and Minority Ethnic communities. We have recruited thousands of Scottish Dementia Friends who want to take action to support people living with dementia.
- Earlier Diagnosis:** Our ongoing 'Let's Talk About Dementia' campaigning at events and on social media is addressing the barriers of stigma and lack of awareness about dementia or the help available, that mean people with dementia do not get a diagnosis early enough to put in place the supports they need to live as well and as independently as possible with the illness.
- Post Diagnosis:** In 2011 we published the 5 Pillars Model of Post Diagnostic Support. The Model describes the support required to build resilience in someone newly diagnosed with dementia to live as well and independently as possible. It was adopted by the Scottish Government as the template for implementing their guarantee of at least one year's post diagnostic support – provided, as our model suggests, by a named, skilled Link Worker. Alzheimer Scotland colleagues are working hard to see this guarantee is delivered.



Alzheimer Scotland's vision for change prioritises six key areas to focus on to ensure the highest quality of care, support and treatment for people with dementia from diagnosis to end of life.

© Alzheimer Scotland



The ADPM recommends the introduction of an Advanced Dementia Specialist Team to provide expert input to existing care and support providers so that they are able to respond to the increasing complexity and intensity of needs as dementia advances.

- Integrated Care:** From our work with people living with dementia, Alzheimer Scotland knows that if care is properly coordinated, integrated, and appropriately delivered, people living with dementia can be supported to stay in their own homes for longer, with a better quality of life. Coordinating care properly also provides efficiencies for providers, enabling better use of resources. To capture this, Alzheimer Scotland developed the 8 Pillars Model of Community Care in 2012, which describes all the elements required across health, social care and informal supports, coordinated by one of the key professionals involved acting as a Dementia Practice Coordinator. This model is being tested in five sites across Scotland as part of the Scottish Government's current National Dementia Strategy.
- Advanced Illness:** The final building block of transformational change is our new Advanced Dementia Practice Model. This builds on the 8 Pillars Model, emphasising the importance of integrated, coordinated care and support. In advanced illness, symptoms become more complex and intense and transitions may be rapid. The Model therefore sets out an approach that enables continuity of care and support, and promotes the wellbeing and quality of life of both the person with dementia, and those closest to them. It combines the skill and understanding of existing care providers, with a Dementia Practice Coordinator, and introduces a multi-disciplinary, expert Advanced Dementia Specialist Team to enable optimum care.

From the point of diagnosis to end of life, every person with dementia and their family deserves nothing but the best care we have at our disposal. To achieve this we must change our current practice and transform our system. We look forward to working alongside our many partners to test and refine this new model.

'The Advanced Dementia Practice Model offers the key to ensuring people with dementia have the best possible end of life.'

More info

The report and summary are available to download at www.alzscot.org/ADPM

National Dementia Dialogue 2015: have your say



Participants at the Dementia Dialogue event in Dumfries.

During 2016 the Scottish Government will produce Scotland's third national dementia strategy. To help inform the next strategy, Alzheimer Scotland has been working in partnership with the Scottish Government to host a series of dialogue events across Scotland. The events in Hamilton, Aberdeen, Fort William, Edinburgh, Stirling and Dumfries have provided the opportunity for anyone with an interest in dementia to have their say in shaping the key priorities for transforming the lives of people with dementia, and those who care for them, in the next national strategy.

Alzheimer Scotland's Policy and Engagement Managers and Dementia Advisors have also been hosting smaller local discussions with local groups to make sure that as many people with dementia and those who care for them are able to participate in the national dialogue.

Alzheimer Scotland has a clear vision for change which has been informed by our members and our local and

national groups representing people with dementia and carers. Our vision sets out the change required if people with dementia and those who care for them are to be properly supported in Scotland, and if their human rights are to be respected. Timely, skilled and well-coordinated support from diagnosis to end of life care is essential if we are to avoid the human, societal and the financial costs of crisis-driven care. Alongside that we must continue work to improve the care of people with dementia in hospital, and other care settings and we must continue to support the development of dementia friendly communities.

A key theme of the dialogue events so far has been the importance of ensuring that national priorities for improving the lives of people with dementia are delivered at local level within the new integrated health and social care partnerships. These partnerships decide how resources for adult health and social care are spent in your local area, so having your say

has never been more important if we are to deliver the transformational change set out in our vision.

These events are only part of the dialogue so don't worry if you have been unable to attend any. You can still have your say by emailing us at publicpolicy@alzscot.org or by writing to Alzheimer Scotland at 22 Drumsheugh Gardens, Edinburgh EH3 7RN. We will collate the information and pass it to the Scottish Government. To make sure that you have your say please send us your views before the end of January 2016.

'our vision sets out the change required if people with dementia and those who care for them are to be properly supported in Scotland.'

A guide to Alzheimer Scotland's education and research work

Valuing dementia research

At Alzheimer Scotland we understand the value of research. The promise of things getting better is something we all pin our hopes on. That's why Alzheimer Scotland has a strong commitment to supporting dementia research taking place in Scotland.

For many of us when we hear the word "research" we think of scientists in lab coats squinting down a microscope, but research comes in many forms. Research is not only about scientific and clinical developments, but also work to improve practice and delivery of care. Alzheimer Scotland is committed to making advancements across all of these disciplines.

With this in mind, we help to fund a diverse range of research.

Scientific and clinical research

We work in partnership with the University of Edinburgh to fund The Alzheimer Scotland Dementia Research Centre. The Centre is now into the final year of an initial five year partnership. The success of the Centre means that our Trustees have agreed to the extension of the Partnership for a further five years. Led by Professor John Starr, it has established an impressive programme of scientific and clinical research and collaborations. The Centre's successes to date helped to attract further grant funding from the Dementias Platform UK to University of Edinburgh.

Policy and practice

Our work in conjunction with the University of the West of Scotland has a strong focus on advancing health and social care dementia practice. Working together at the Centre for Dementia Policy and Practice, our organisations

are exploring how education, applied research and social enterprise can help people to live well with dementia. Policy and Research Advisor Barbara Sharp is a key figure at the Centre for Dementia Policy and Practice, where her job is co-hosted by Alzheimer Scotland and the University.

'In a ground-breaking strategic alliance with Queen Margaret University, we're working together to ensure that healthcare students receive a robust education in dementia.'

This summer, Barbara graduated with a doctorate in nursing, having completed a PhD research study entitled: Stress as Experienced by People with Dementia. The study involved people with dementia as active research participants and careful analysis of their accounts of experiencing stress. Look out for a feature on this very interesting piece of work in our spring magazine.

In a ground-breaking strategic alliance with Queen Margaret University, we're working together to ensure that healthcare students receive a robust education in dementia. (see page 14) Each year we also fund 15 scholarships at three Scottish universities – the University of Edinburgh, the University of Stirling and Queen Margaret University.

Making connections

In addition to this, Alzheimer Scotland continues to build strong relationships with dementia researchers across Scotland.

The Scottish Dementia Research Consortium (SDRC), established in 2013, is an umbrella organisation for all dementia researchers in Scotland. It promotes collaboration and represents Scottish dementia research at a UK and international level. Alzheimer Scotland is proud to provide developmental support to the SDRC.

Alzheimer Scotland also supports a number of doctoral training programmes including an evaluation of therapeutic approaches for people with dementia at Queen Margaret University, and investigation of the digital contribution to dementia friendly communities at the University of Stirling.

By investing and working across all of these disciplines we are striving to build a brighter future for people with dementia now and in the future.



Queen Margaret University students Chris Cousins and Mairi Ferrier have gained valuable insight into working with people with dementia through Alzheimer Scotland initiatives.

'our organisations are exploring how education, applied research and social enterprise can help people to live well with dementia.'

More info

If you would like to make a donation to our research work visit www.alzscot.org/donate

Switching the lights out one by one – how epigenetics is changing our understanding of dementia

Professor John Starr, Director of the Alzheimer Scotland Dementia Research Centre, shares an update on some recent research work.

The last 50 years has seen a revolution in medical science, the Genetics Revolution. The pace of this revolution is ever increasing with a whole range of new genes implicated in the causes of different dementias over the past five years.

But here's the big question: we all developed from a single cell at conception and the DNA, the basic genetic code, derived only from that cell is the same throughout all the cells in our body. So why don't our toes look like our eyes nor our livers work like our hearts even though they contain this identical genetic code?

The reason is that not all the code is necessary for any individual cell; there are sections of code important for liver cells and other sections important for heart cells, and some relatively small sections important for all our cells. It is crucial that liver cells don't start using the genetic code for heart cells and vice versa. To prevent this, there are a number of what might be thought of as 'switches' that can switch on or off specific regions of the genetic code. The mechanisms responsible for these switches fall under the umbrella term epigenetics, epi just means 'on'. We, at the Alzheimer Scotland Dementia Research Centre have been studying one of these epigenetic mechanisms and how it might relate to dementia.

What we are doing

DNA, the basic genetic code, is made up of the elements carbon, hydrogen, oxygen and nitrogen assembled in simple units called bases. We have chosen to look at the way these DNA base pairs are methylated. A methyl group is a simple chemical structure



comprising one carbon and three hydrogen atoms that can replace a single hydrogen atom of the DNA base pair unit. This is known as methylation. When DNA is altered like this, it can no longer be read to make proteins that function within the cell.

At the Alzheimer Scotland Dementia Research Centre, we have been working with a sample group of around 1,000 people in the Edinburgh area to measure these changes to the structure of the DNA.

The group we're working with were all born in 1936, so they are known as the Lothian Birth Cohort 1936 (LBC1936) and this group is one of the cohorts now part of the Dementias Platform UK. The Dementias Platform UK is funded by the Medical Research Council to identify people at risk and in the early stages of dementia, and we are doing this for the LBC1936 cohort. In fact, Dr Ruth Sibbett is funded by Alzheimer Scotland to do just this.

As a first step we have measured how much of the DNA is methylated (i.e. changed) in the LBC1936 at age 70 and age 73 years.

What we have found

We have found that the amount of DNA methylation not only predicts how long you live, a kind of 'epigenetic clock', but that those people all born in the same year who had more DNA methylation scored less well on a range of tests of mental ability. They also scored less well on measures of physical fitness such as lung function and walking speed. Although there was around a 10% increase in the amount of methylation between 70 and 73 years, the degree of change was not associated with the degree of decline in mental abilities of the same three year period. The full results are published in the International Journal of Epidemiology.

What this means

The degree that genes are being switched off in these older adults relates to the decline in their mental abilities and although we didn't detect any association between the change in methylation and cognitive decline,

this is probably because three years is too short a period to detect this in otherwise healthy people. However, the observations can be best explained by loss of function from genes that protect against cognitive decline because they have been switched off. It is as if the brain is like a house and one by one its lights are being switched off. The next step is to discover the specific 'switches' that are responsible and we are fortunate that the Biotechnology and Biological Sciences Research Council (BBSRC) has funded the characterisation of the entire DNA code for the LBC1936.

'The race is on to solve this complex puzzle, a race that we at the Alzheimer Scotland Dementia Research Centre are currently leading.'

Hope for the future

Prevention is better than cure they say, and we need to identify the epigenetic mechanisms that are protecting against dementia. In another study published by the Centre this year (Russ T et al. Epidemiology 2015;26:263-270), we showed that identical twins who have the same DNA can be 2-3 times at different risk of dementia depending where they lived. This indicates environmental factors have a strong influence on who develops dementia and these environmental factors are likely to be acting, at least in part, by switching on or off epigenetic switches. So the race is on to solve this complex puzzle, a race that we at the Alzheimer Scotland Dementia Research Centre are currently leading, with a prize of reducing dementia rates for generations to come that we would all like to win.

What your donation could be used for:

£25	Provides storage for a blood sample that can be used by future researchers
£100	Funds a researcher to carry out specialised memory tests for early detection of dementia
£500	Funds a cutting-edge brain scan to look at the causes of dementia
£1,000	Provides a small start-up fund for new research studies
£5,000	Allows us to share the results of our research with policy makers, people with dementia and their carers
£10,000	Funds a dementia specialist PhD studentship for 6 months



Professor John Starr, Director, Alzheimer Scotland Dementia Research Centre.

More info

Find out more about the Alzheimer Scotland Dementia Research Centre www.alzscotdrc.ed.ac.uk

To participate in research, sign up to Join Dementia Research

www.joindementiaresearch.nihr.ac.uk

Donate to Alzheimer Scotland to support our research activity www.alzscot.org/donate

Christmas Lecture

In December we welcomed Professor Craig Ritchie, Chair of the Psychiatry of Ageing and Director of the Centre for Dementia Prevention at The University of Edinburgh, to speak at Alzheimer Scotland's annual Christmas Lecture. The theme of his lecture was 'Prevention: Keeping it Real' and it took place in the festive surroundings of The Hub in Edinburgh.

At the outset of the hour-long lecture, Prof. Ritchie explained that it was his mission to convince the audience that there are certain things that we can all do to reduce our risk of developing dementia. He acknowledged that we are confronted by confusing messages on an almost daily basis in the media about risk reduction and prevention. He then took listeners on a tour of different potential risk factors, including gender, family history, alcohol, sugar intake, high blood pressure etc.

He also looked at how researchers all over the world are examining these elements and carrying out research to increase our understanding. He



emphasised the importance of signing up to clinical research, saying that researchers need "lots and lots of data on lots and lots of people".

The lecture stressed that researchers can deliver a roadmap on prevention but that it is up to governments, food and leisure industries, and public health bodies to use the map. Professor Ritchie concluded: "Relatively speaking, the science is easy. The tough part is

getting people to listen to what the science says."

More info

To register your interest in taking part in dementia research, visit www.joindementiaresearch.nihr.ac.uk

To find out more about dementia risk reduction, visit www.alzscot.org/riskreduction

9th Annual Scottish Conference on Dementia in Younger Adults

The 9th Conference on Younger Adults with Dementia took place at the Iris Murdoch Centre in Stirling. Since its beginning, the conference has been enthusiastically organised by Dr Gary Stevenson, a Consultant Psychiatrist based at NHS Fife.

There was a varied, interesting and, at times, challenging programme for the audience exploring research, services and the experiences of those living with younger onset dementia. Topics included a compassionate but highly informative explanation of speech and language difficulties and a presentation on the importance of post diagnostic support from NHS Fife.

There were also presentations on developing new methods to improve diagnosis and an exploration of vascular risk factors amongst younger people.

But the most moving, thoughtful and painfully honest presentation came from Doreen Parker, carer of her husband who developed frontotemporal dementia. Doreen spoke eloquently about the impact on her husband and family, particularly in relation to the heritable nature of her husband's condition. Doreen's story reminded everyone attending of the reasons why the search for better diagnosis, treatment and support is so vitally important.

The 10th annual conference next year promises to be a fascinating look back over the progress that has been made in younger onset dementia.



Photo courtesy of Tony Marsh.

Shifting the paradigm

A three pronged approach to transformational change in acute hospital environments.

Being in acute general hospital environments can be difficult and distressing at the best of times, but even more challenging for people with dementia, their families and carers.

Over the last few years Alzheimer Scotland has been working with our partners in Scottish Government, NHS Scotland and Scottish Social Services Council (SSSC) on a three-pronged approach to transforming the experience of people with dementia in acute general hospitals. This transformation is centred on a team of Dementia Nurse Consultants, Dementia Champions and a 10-point action plan.

At a strategic level, Alzheimer Scotland Dementia Nurse Consultants (DNCs), plus National Allied Health Professional Consultants (NAHPCs) are working with NHS health boards across Scotland to ensure the objectives of Commitment 10 of the national dementia strategy are being delivered locally. Their remit is to ensure hospitals create conditions that allow their staff to welcome people with dementia into their care and ensure that they feel confident and comfortable when caring for people with dementia. These dementia specialists are playing a vital role in guiding the dementia-related strategic decisions of their NHS Boards and in progressing the national agenda for improving standards and the experience of dementia healthcare in Scotland's acute hospitals. Alzheimer Scotland and the Scottish Government operate in partnership to fund and support these posts and we now have an Alzheimer Scotland Dementia Nurse Consultant/Specialist in almost all of the 14 NHS Boards. We also have three Allied Health Professional Consultants focussing on dementia care.

On the wards, Dementia Champions have been trained to deliver dignified and personalised care to patients with dementia. They act as agents for change in improving the experience, care,



treatment and outcomes for people with dementia, as well as inspiring and supporting their colleagues around them. Working with our partners at NHS Health, Scottish Social Services Council and the University of the West of Scotland, we have trained over 600 Dementia Champions across Scotland and a 7th cohort will graduate in March 2016.

At the heart of this change process is a 10-Point Action Plan which was outlined in Scotland's National Dementia Strategy 2013-16 (pictured right).

In 2015 the team of DNCs were joined by Maureen Taggart as a new National Dementia Nurse Consultant. A key priority for Maureen is to develop a model for change and improvement within long-term dementia care environments. This group often has complex needs and Maureen is exploring highly therapeutic, multi-disciplinary and alternative solutions with our NHS partners.

More info

A review of the work of the Alzheimer Scotland Dementia Nurse Consultants and the Allied Health Professional Consultants in 2015 will be available soon on the Alzheimer Scotland website www.alzscot.org

10 Dementia Care Actions in Hospital



1 Identify a leadership structure within NHS Boards to drive and monitor improvements

2 Develop the workforce in line with Promoting Excellence

3 Plan and prepare for admission and discharge

4 Develop and embed person-centred assessment and care planning

5 Promote a rights-based and anti-discriminatory culture

6 Develop a safe and therapeutic environment

7 Use evidence-based screening and assessment tools for diagnosis

8 Work as equal partners with families, friends and carers

9 Minimise and respond appropriately to stress and distress

10 Evidence the impact of changes against patient experience and outcomes

Developing the dementia workforce

Elaine Hunter, National Allied Health Professionals Consultant at Alzheimer Scotland is leading on the agenda to bring the skills of the Allied Health Professional (AHP) workforce to the forefront of dementia care. Her work with Occupational Therapists and AHPs is crucial in making sure that people training to enter these professions are equipped to understand and deliver the high standards of support and care that we advocate in our policy work.

Here, Elaine updates us on ongoing partnership work with universities in Scotland.



Queen Margaret University MSc students with Henry Simmons and Elaine Hunter (centre).

At the beginning of 2015 we signed a strategic alliance with Queen Margaret University (QMU). The alliance sees us taking a three-pronged approach to improve student understanding of dementia: firstly, working broadly with all staff and students to make QMU a dementia-aware higher education institution; secondly, developing opportunities for health and social care undergraduates to learn about dementia; and thirdly, creating continued professional development opportunities for AHPs so dementia care is viewed as an attractive profession with clear opportunities for career progression.

Over the past 12 months we have made great progress in developing our offering to QMU students. Together with the university we have created the first ever jointly branded and co-produced MSc module on "Developing Rights-Based Practice for Allied Health Professionals working with People Living with Dementia, their Families & Carers".

The module includes sessions delivered by Alzheimer Scotland. Chief Executive, Henry Simmons leads a session on the policy landscape around dementia and health and social care.

while I lead a debate on how we can put policy into practice and what adjustments we need to make on the ground to implement these changes.

AHP students who complete the MSc should find that they have enhanced career development opportunities because their skills and knowledge in this area are in high demand as the need for specialist services for people with dementia increases. All students who participate in the MSc are offered an Alzheimer Scotland bursary which covers half of their course fees and gives them membership of Alzheimer Scotland with access to newsletters and other important updates.

In December we opened a Dementia Information Centre in QMU library so that information and resources about dementia are readily available to staff, students and the general public who use the library.

We are also developing an exciting new partnership with the University of Strathclyde. At the end of 2015 we had the great pleasure to welcome, for the first time ever, 26 first year Speech and Language Therapy students into five of our services in the west of Scotland. The speech and language

therapy students from the University of Strathclyde spent two afternoons taking part in experiential visits linked to an assignment looking at how charity organisations approach communication and dementia.

'All students who participate in the MSc are offered an Alzheimer Scotland bursary which covers half of their course fees and gives them membership of Alzheimer Scotland with access to newsletters and other important updates.'

More info

For more information contact Elaine at ehunter@alzscot.org

Let's talk about dementia online

Do you know about our Let's Talk About Dementia blog? Launched in June 2014, the blog provides a platform for our Allied Health Professional (AHP) colleagues to talk about their work and share learning. Each Thursday we publish an article from a different contributor looking at various aspects of their work.

Over the past 18 months it has proved to be a great resource for both AHPs and the wider public who want to gain a better understanding and appreciation of their fantastic work. From diet and health to community activities – AHPs possess a wealth of knowledge and skills, yet often

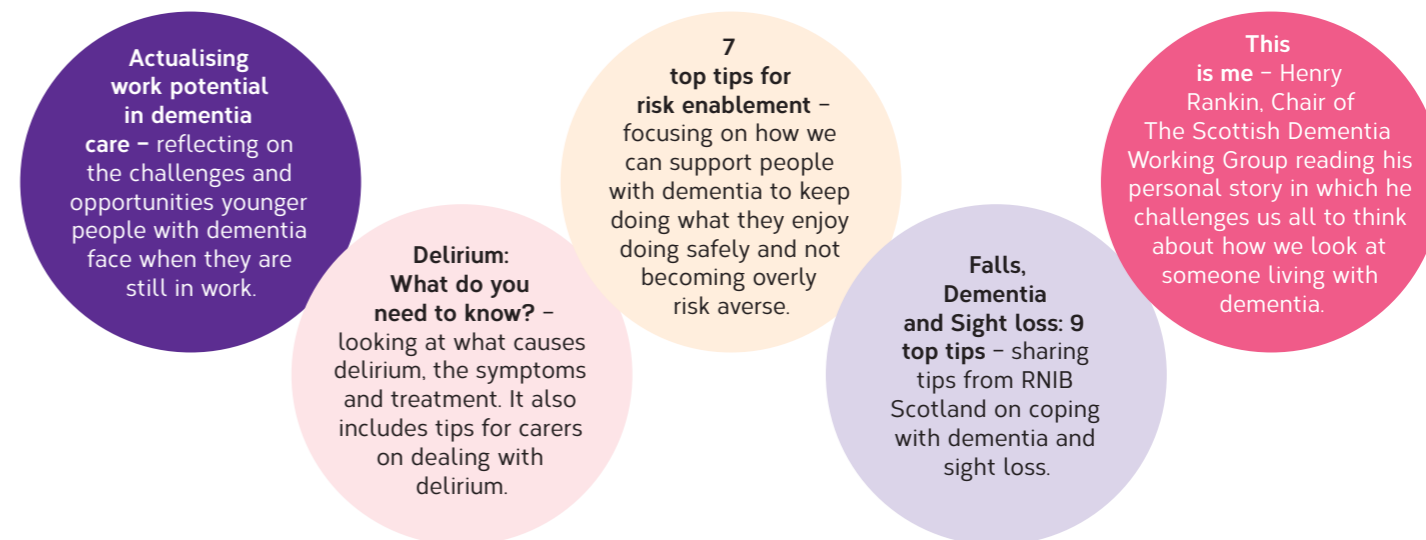
continue to remain 'hidden treasures' to many outwith their field.

To date we've welcomed over 40,000 visits to the blog, and published 78 articles.

More info

Visit the Let's talk about dementia blog at www.letstalkaboutdementia.wordpress.com
To join the conversation and read what our contributors have to say, go to www.alzscot.org/talking_dementia and enter your email address to get new posts by email.

The top 5 blogs of 2015 were:



Meet our Policy and Engagement Managers

Alzheimer Scotland has staff working across Scotland to make sure the interests of people with dementia, their families and carers are being represented at a local level. They lobby and negotiate with local authorities to make sure that people living with dementia receive access to the support and services they are entitled to. They engage with our members, with people with dementia, their families and carers to ensure they have local voice and they also raise funds to support our work across Scotland. If you would like to speak to us about a local issue, here's who to get in touch with.

Arlene Crockett , Glasgow, East Dunbartonshire and Lanarkshire (north and south)	0141 410 0102 acrockett@alzscot.org
Gerry McCoy Ayrshire, Dumfries and Galloway	01563 590475 gmccoy@alzscot.org
Jean Armitage , East Renfrewshire, Renfrewshire, West Dunbartonshire and Argyll & Bute	0141 410 5308 jarmitage@alzscot.org
Judy Corbett Falkirk, Stirling, Clackmannanshire and Fife	01592 803804 jcorbett@alzscot.org
Karen Steel Highland, Western Isles and Orkney	01349 808650 ksteel@alzscot.org
Ruth McCabe Edinburgh, Lothians and Borders	07867 180185 rmccabe@alzscot.org
Gabrielle Colston , Aberdeenshire, Grampian, Tayside, Shetland, Perth and Kinross	01382 210013 gcolston@alzscot.org

Alzheimer Europe conference: sharing learning across Europe

Each year, Alzheimer Europe organises a Europe-wide conference. This year, the 25th Alzheimer Europe Conference was held in Ljubljana in Slovenia from 2-4 September.

Over 570 people attended the conference and the programme included 150 speakers. The theme of the conference was "Dementia: putting strategies and research into practice".

The Alzheimer Europe conference is an important annual event which helps organisations, professionals, and people with dementia from around Europe share information and best practice, and build a brighter future for people with dementia in Europe.

Scottish delegates to the conference included members of the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN). They were helped to attend by the Life Changes Trust, who were kind enough to provide bursaries to enable people with dementia and carers to take part in this wonderful experience.



Delegates attend the 25th Alzheimer Europe Conference in Slovenia.

Scottish carers loved Slovenia

NDCAN was pleased to send four representatives to the Alzheimer Europe conference – Diane Goldberg and Jeanette Maitland accompanied Chair Irene Oldfather and Vice-chair Lorna Walker to Slovenia. For NDCAN members this was a not-to-be-missed opportunity to spread the message about people caring for loved ones with dementia.

Reflecting on the conference, Irene said: "It was a very positive experience. I really enjoyed the chance to network with a wide range of people."

Jeanette commented: "Attending the conference helped me to realise how much progress had been made since my husband was diagnosed. I appreciated the opportunity to reiterate the fact

that you can live well with dementia and to spread the message of the great work being done in Scotland."

Fellow carer Diane agreed that the conference provided a great platform to meet people, build new relationships and strengthen existing relationships, saying "It was important to me to hear what is happening and raise awareness of carers for younger people with dementia. My mum was just 54 when she was diagnosed."

One of the highlights of the conference was designing the NDCAN display table for the exhibition. Lorna has always "shared the love" of the carer experience, and was delighted to notice that the word LOVE features in the name SLOVENIA.



NDCAN members Jeanette Maitland and Lorna Walker share the positive aspects of caring for people with dementia.

People with dementia shared transport report

The SDWG shared their work on travelling with dementia at the Alzheimer Europe Conference, which was very apt as nine members undertook the 12 hour journey to Slovenia by plane, train and automobile!

Here's what Nancy McAdam, long-standing member of the SDWG had to say about the experience:

"I was honoured to represent the SDWG and to present our travelling with dementia work. Through funding from the Life Changes Trust, I was able to take my son Scott to support me and I formed a better relationship with him. There were nine of us travelling together from Glasgow. This was a lovely thing to do.

"I learned that while you present you never see yourself because you are on the stage! This was where I saw the benefit of social media because I was able to see myself on twitter and to get

immediate feedback.

"I used the tips I learned from watching one of the other presentations from Alv, a member of the European Working Group of People with Dementia, in my own presentation back in Scotland when I received the Lifetime Achievement Award from Alzheimer Scotland. His advice – be yourself!

"I felt more European following the conference! It was amazing. I learned loads as an individual with dementia and I had lots to say when I came home."



Four SDWG members attended the conference along with three supporters and two staff members.

A melting pot of ideas

Last year, the Alzheimer Europe conference was held in Glasgow, where more than 800 delegates came together to discuss "Dignity and autonomy in dementia".

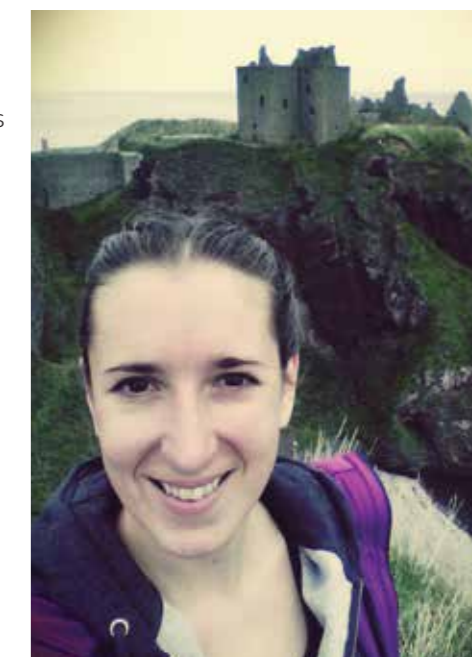
Among those delegates was a young psychologist from Slovakia, Martina Vanova. Attending that conference in Glasgow was to be a major turning point in her life.

"I was working as a psychologist in a day care service in Slovakia and was lucky enough to attend the Alzheimer Europe conference in Glasgow. At the conference I met many people and had very interesting discussions. I learnt that Alzheimer Scotland was a world leader in dementia services. From that moment on it became a kind of dream for me to work for this organisation.

"When my contract in Slovakia was up Alzheimer Scotland was the first place I got in touch with – I really wanted to work there. In July 2015 I was successful with my job application to be an Alzheimer Scotland Link Worker. In my old work everything felt very mechanical. Now at Alzheimer Scotland I am close with my clients, I get to know them and build up a relationship over the year I see them and this is wonderful. I love my job and am so proud to work here!"

More info

The next Alzheimer Europe Annual Conference takes place in Copenhagen from 31 October to 2 November 2016. See www.alzheimer-europe.org for details.



Your gift to future generations

How you can make a difference to the lives of people living with dementia

Right now, there are 90,000 families across Scotland living with dementia. Tens of thousands of people are learning to adjust to the changes that dementia brings. As the illness progresses, many children and grandchildren are learning to live with the "new normal" as relationships shift and they become carers for their parents and grandparents.

And the number of people living with dementia in Scotland is continuing to

rise. Recent research suggests that 1 in 3 babies being born today will go on to develop dementia in later life. There has never been a more important time to think about planning for the future.

Alzheimer Scotland is working harder than ever to make sure nobody faces dementia alone, now and in the future. We know that with your support the future can have a brighter outlook for people with dementia.

Leaving a gift in your will to Alzheimer Scotland is a wonderful way to support our work and help us to continue providing expert care, support and advice so that people with dementia can live the best life possible for as long as possible. Your gift can also bring hope for the future – because we are carrying out vital research that could one day lead to a cure.



'Leaving a gift in your will to Alzheimer Scotland is a wonderful way to support our work and help us to continue providing expert care.'

Here are three ways that gifts from wills have helped us over the past year



Fighting for change

Fighting for the rights of people with dementia and their carers is a vital strand of our work. We support the Scottish Dementia Working Group and National Dementia Carers Action Network. These campaigning groups ensure the voices of people with dementia and their carers are heard at local, national and international levels of government. We are also working to support people to take part in campaigning and activism at a local level so people are heard by local authorities, health boards and other decision makers. Our Dementia Nurse Consultants are working at the highest levels to embed high standards of care in the culture of NHS hospitals.



Research and education

Working with partners at universities across Scotland we support research to improve care and to discover potential new treatments. Together, with the University of Edinburgh, we fund the Alzheimer Scotland Dementia Research Centre and support their impressive programme of scientific and clinical research and collaborations. We also fund the Centre for Policy and Practice at the University of the West of Scotland and 15 postgraduate bursary placements and fellowships each year at the University of Edinburgh, the University of Stirling and Queen Margaret University.



Personalised support and information

We rely on gifts in wills to help fund our personalised support and information services such as our Dementia Advisors, Dementia Helpline, Dementia Cafes, Memory Buses, therapeutic activity groups, peer support and befriending. Every person living with dementia has different needs and experiences a different journey with the condition. Our support services provide tailored help and enjoyable experiences to make sure that people living with dementia can have the best possible quality of life.



Share our vision for the future

Alzheimer Scotland has a clear vision of what's needed if we are to avoid the human and economic crisis that dementia will bring in the future. Leaving Alzheimer Scotland a gift in your will helps us to keep influencing policy changes on behalf of people living with dementia and campaign for quality care, as well as providing continued support to people living with dementia their families and carers, and investing money in research so that we can keep making medical advances in the pursuit of a cure.

You don't need to be wealthy to

make a difference. You may feel unable to leave a large sum of money to Alzheimer Scotland. We are grateful for any and all gifts that we receive. We need to raise £15,000 every day to fund our vital services, so every pound counts.

Leaving a gift to Alzheimer Scotland in your will is not just a gift to us, it is a gift to future generations living with dementia.

We recommend that you consult with a solicitor to ensure that all the legal formalities are correctly followed and your will is valid.

More info

To order your Legacy Pack or to discuss leaving a gift to Alzheimer Scotland in your will, contact Catherine Thomas on 0131 243 1453 or email cthomas@alzscot.org. For tips on planning for your future, see p26.

Creating Dementia Friendly Communities in Dumfries and Galloway

Thanks to a generous grant from the Life Changes Trust, Dumfries and Galloway is continuing its journey towards becoming a Dementia Friendly Community. The grant has enabled Alzheimer Scotland to recruit a team of four part-time Locality Workers – Karen Anderson, Rachel Byers, Gladys Haining and Jill Rennie, alongside Crawford Little from User and Carer Involvement. They will spend the next three years working across Dumfries and Galloway, under the management of Community Development Manager, Kenny Degnan, a well known figure in the area from his many years in the local police force.

The project got off to a flying start on 28 October with an official launch in the centre of Dumfries. Working from our Memory Bus, the new team spoke to shoppers and staff in local businesses, handing out fliers describing the aims of the project and

inviting people to get involved. Our mascot Buddy also came along to support the event.

Speaking at the launch, Kenny said "The project is a partnership between Alzheimer Scotland, Dumfries & Galloway Council, NHS Dumfries & Galloway and UCI (User and Carer Involvement) but we need as many people as possible to take part – as individuals, in community groups and organisations of all kinds and in local businesses – to make our region a place where people with dementia and their families feel valued, supported, empowered and understood in their communities, regardless of where they live."

As well as working with local groups and businesses, the team will be offering Dementia Friends information sessions that members of the public can attend.



The Dumfries Dementia Friendly Community team take to the streets to promote the new project.

More info

Anyone living in the Dumfries and Galloway area who would like to know more or who wants to get involved with the project should contact Kenny Degnan at our Dumfries Dementia Resource Centre on 01387 261303 or by e-mail at kdegan@alzscot.org

More milestones for Dementia Friends Scotland

Dementia Friends Scotland continues to grow, with us now having recruited over 16,000 friends. We have been overwhelmed by the level of interest as well as the feedback we have received regarding the programme. The business world has grabbed this with both hands recognising how this could make a difference not only to their customer service strategies but also importantly to their employees, who may be supporting a person with dementia on a personal level. We have received many testimonials from companies we have been working with, in particular Sainsbury's Bank. Anne McWhinnie, Dementia Friends Programme Manager, has now delivered over 12 sessions to the Lochside branch of Sainsbury's Bank.

Anne said "I have been overwhelmed by the commitment that Sainsbury's Bank have made in terms of creating Dementia Friends within their



Employees at Sainsbury's Bank celebrate becoming Dementia Friends.

organisation. We have established a close working relationship. I have also been afforded the opportunity to offer more bespoke support for employees by organising one to one clinics to discuss the support network that Alzheimer Scotland can offer."

One of the team at Sainsbury's Bank commented: "I found this a

great session. I gained an overview of dementia and how we as society need to be more aware and tolerant in the community to provide support to those with dementia to help them to continue to take part in everyday life rather than being isolated in the community. I'd highly recommend it to others as an awareness piece"

This October, staff at Wishaw General Hospital set a Dementia Friends Scotland record by clocking up 508 Dementia Friends in the workplace. Having so many staff in the hospital who are dementia aware is a powerful statement that Wishaw General Hospital cares about its patients, and their families and friends who are living

with dementia.

Gillian Corbett, Chief of Nursing Services at Wishaw General Hospital said: "We're so pleased to have set this record. We've been committed to achieving this goal since we started working with Alzheimer Scotland to create Dementia Friends among our staff at the hospital. We're already

seeing positive changes in the way that our nurses are interacting with patients and their families."

More info

Find out about Dementia Friends Scotland at www.dementiafriendsscotland.org

Dementia Resource Centres

In 2015 we launched four new Dementia Resource Centres (DRCs) around Scotland in Lerwick, Tain, Dingwall, and Aberdeen, which brings the grand total of centres across Scotland to 18. These centres are hubs for information, resources, advice and services and anyone can pop in off the street and ask for help. Our Dementia Resource Centres complement our 38 services where Alzheimer Scotland staff plan and deliver dementia support groups and projects.

Our new Dementia Resource Centre in Aberdeen was officially opened on Monday 21 September, World Alzheimer's Day. Anne Duncan, whose husband Bill is supported by the Centre, said, "I'm so glad that this new Centre has opened in Aberdeen. Alzheimer Scotland have been a wonderful support to Bill and I; they've been a great help. This new Centre means that even more people like us will be able to get the support we need here in Aberdeen."

2016 will see more new centres opening in Angus, Helensburgh and Glasgow.

The majority of the funding we need to open these centres is raised by local communities, because they understand how important it is to have dementia services visible on their high streets. We still need contributions to help us get the Angus, Helensburgh and Glasgow DRCs up and running. If you can help fundraise for us please get in touch. Every penny counts.



Guests celebrate the opening of the Aberdeen Dementia Resource Centre.

Grandfather, Grandson. Father, Daughter.

There are two books to recommend in this edition.

The first is a children's book – **"Grandpa's Great Escape"** by David Walliams (of Little Britain fame). It centres on the relationship between said Grandpa and his Grandson Jack. Jack loves to hear his Grandpa's tales of World War II as a fighter pilot and as Grandpa's dementia starts he regresses to those days more and more. It is a funny and engaging book for children, young adults, parents and grandparents. It has intergenerational appeal and does bring humour to a sensitive subject.

Without giving the plot away,

the 'great escape' does take a Steve McQueen slant after Grandpa moves into a care home.

The second book is actually a play called **"The Father"** by Florian Zeller. This time it focuses on the relationship of a father and daughter as dementia sets in.

It is a powerful play both on the page and on the stage. It was adapted in London in 2015 to almost unanimously positive reviews. The father was played by Kenneth Cranham (Shine on Harvey Moon) and the daughter by Claire Skinner (Outnumbered). The staging covers the father's life from 20



to 70 but tells his story out of sequence, which contributes to the confusion to reflect the dementia. It's a short book but well worth a read. The play is transferring to Broadway in 2016, and then hopefully back to the UK to tour.

Decoding Dementia with young people

What do young people in Scotland think about dementia? This is the question we posed this summer when we began the Decode Dementia project in partnership with Young Scot, Scotland's information and citizenship charity for young people.

Using creative and innovative co-design methods, we spoke to young people across the country, inviting them to share their views and experiences of dementia, and also help us understand how we can encourage young people to talk about dementia.

As part of the project young people were invited to submit a 'Dear Dementia' letter, explaining how they felt about the condition. The response was overwhelming with over 140 people writing in so far. Lisa Murphy, Co-design Manager at Young Scot said "This is one of the most powerful and insightful responses we've had to an activity like this. Dementia is clearly something that matters very much to young people in Scotland."

In October, over 25 young people joined us in Glasgow. The group was mixed between people who had personal experience of dementia and



those who didn't. They explored their attitudes to dementia and talked about what can be done to help young people understand dementia. There were lots of great ideas for future intergenerational projects – so watch this space!



Around the world

Global Alliance on Women's Brain Health

The Women's Brain Health Initiative Canada, WomenAgainstAlzheimer's USA, Alzheimer's Research UK, and 21st Century BrainTrust® announced that they have formed the Global Alliance on Women's Brain Health to raise awareness of women's brain health challenges and significantly expand funding for sex-based brain health research, that benefits both men and women.

The Global Alliance on Women's Brain Health will define a scientific agenda, drive new funding for research, and convene scientific leaders to ensure the most rapid and effective scientific strategies in women's brain health. It will also raise awareness of the importance of gender-sensitive focus and investment.

"The latest research confirms dementia develops faster in women than in men, women are more vulnerable to Alzheimer's, and not just because we live longer," said Lynn Posluns, President, Women's Brain Health Initiative. "What is not clear, though, is why. If scientists can figure out the mechanism that causes more Alzheimer's disease in women, they might be able to develop treatments that halt the process. This is the type of research the Global Alliance will fund, for a healthier outcome for both men and women."

The Global Alliance on Women's Brain Health also plans to expand to regions outside of North America and the U.K., including Africa and Asia

Inspirational Japanese dementia initiative celebrates 10 years



Last year, Japan celebrated 10 years of its Dementia Supporter Caravan initiative. The programme, which started in 2005 now

boasts 6.1 million members. A world-first, the programme encourages people to learn about and understand dementia, and then inspire friends, family and colleagues to do the same.

From apartment managers to bank employees, retailers and children, millions of people across Japan have taken the government-funded course to learn about dementia and how they can make small changes in their behaviour to help people living with dementia.

The Dementia Supporter Caravan initiative is the model for many programmes rolled out across the world, including our own Dementia Friends Scotland programme which now has over 16,000 members.

We wish our friends in Japan all the best – they have a target of 8 million Dementia Supporter Caravan members by 2017 and we're sure they'll reach it!

Alzheimer Europe surpasses campaign target

Over the last year, Alzheimer Europe has been gathering signatures on the Glasgow Declaration – a petition to ask European leaders to implement a Europe-wide dementia strategy.

In November it reached, and surpassed, its target of 10,000 individual signatures.

A spokesperson from Alzheimer Europe said: "We would also like to thank everyone who signed the Glasgow Declaration. We hope to make your voices heard in Brussels, and to move a step closer to a European Dementia Strategy. We will keep you posted on our progress!"

A European Dementia Strategy would see the introduction of a rights-based approach to providing care and support to people with dementia, their families and carers across Europe. Achieving this would be an incredibly important milestone.

'We hope to make your voices heard in Brussels, and to move a step closer to a European Dementia Strategy.'



Looking after yourself: a carer's perspective

Muriel Reid talks to us about the importance of looking after yourself and knowing what you're able and willing to do when someone you love has dementia.

When my mum Betty was diagnosed with Alzheimer's disease 6 years ago, I sort of put the shutters up. I don't mean that I ignored my parents or anything like that – we've always been a very close family. I mean that I didn't want to know the ins and outs of what was ahead, from a medical perspective.

Although I am an acute care nurse I actually didn't know that much about dementia at the time, and with my mum's diagnosis it felt like not knowing was easier than knowing. Instead I threw myself into fundraising for Alzheimer Scotland, running a 10k and taking part in a bike race in Manchester. That was my way of dealing with mum's diagnosis.

My parents are in their 80s and were able to live well with my mum's dementia for a good few years. My dad, John, looked after mum at their home in Stirling and there was a great care package in place to help him to do that.



'Building them a special home where they can continue to live together for as long as possible was the main reason behind it all.'

A couple of years ago he started looking for a smaller house that was going to be more manageable for them. After a few months of looking he hadn't seen anything suitable. One night when they were visiting he joked about moving into a "granny flat" in my family's garden. It was just a joke, a throw-away comment, but it stuck with me and played on my mind over the next few days until I thought "why not?"

I live in Heriot in the Borders with my husband Gary and our three children, Lucy (15), Matt (12) and Holly (9). I spoke

to them about the suggestion. We've always kept the kids informed and involved with my mum's condition. They were keen on the idea so I spoke to dad again and together we came up with a plan. Dad is an architect so it didn't take him long to get started on drawing up the plans for a small bungalow and I had a great friend who was able to help us out with project management.

One of the things that I had to make clear at the start of all of this was that I wasn't able to take on a caring role for mum. Having my parents next door was going to have so many benefits. Building them a special home where they can continue to live together for as long as possible was the main reason behind it all. They've been married for nearly 50 years and it would have been heart-breaking for them to have to live apart now. Some people think because I am a nurse that my mum's care was something I could and should take on, but I have my family and my job and it

would be unfair to try and take on more. I also know that I wouldn't be able to cope physically or mentally if I had to deliver personal care to my mum.

Being a nurse I see family conflicts all the time, especially when people are acutely unwell. I see the stresses that people can be under and what happens when people don't look after themselves. It is a hard thing to do, to draw that line, but I knew I had to do it for the sake of everyone involved.

When mum and dad moved in at the beginning of 2015 things didn't go as smoothly as we had planned. The fantastic care package that had been in place in Stirling didn't transfer seamlessly to the Borders. This led to a really distressing episode where I felt I had to walk out, albeit only for a very short period, to make the point that I wasn't going to take on mum's personal care. In the end the local authority did ensure a full care package was in place. I've since learned that having access to

a Dementia Practice Co-ordinator would have helped us access support and made the whole situation less stressful.

The kids love having their grandparents next door. Matt visits his granny a lot to speak to her and hold her hand. Although she struggles to recognise people now, she has a brilliant bond with him. It's good for her just to have the children about. Holly, our youngest has said "I'm glad granny has Alzheimer's because if she didn't she wouldn't live with us and I wouldn't get to see her every day." It's a funny thing to hear as an adult, but it's really quite sweet. And Lucy has been talking about dementia at school, and encouraging the school to fundraise for Alzheimer Scotland.



'The kids love having their grandparents next door. Matt visits his granny a lot to speak to her and hold her hand.'

For me, I've become more accepting of mum's dementia. In June 2015 I attended the Alzheimer Scotland annual conference where I met the National Dementia Carers Action Network (NDCAN). They are such a brilliant bunch of people and finding my campaigning voice has helped so much. Through them I have learned that talking about dementia can help others, too.

I have also been learning a lot more about dementia. I have taken on the Dementia Link Nurse role at work, helping to make my colleagues more dementia-aware. Approaching it from a professional perspective has been a lot easier than thinking about it in relation to mum. Along with others from NDCAN, I've also taken part in one of the Dementia Dialogue events with

Alzheimer Scotland and the Scottish Government. It has been great to have an opportunity to have a say in developing policy around dementia. A lot of discussion focussed on end of life care, which fits in with my mum's stage of dementia as she is quite progressed now. I feel like I have a lot I can offer and make a difference to families facing this in the future, which is encouraging.

I think the most important things people can do for themselves as carers is to set their boundaries and find an outlet for their emotions. Drawing a line isn't selfish; it just means you're being realistic. And if you don't find a way of dealing with your feelings, you will burst. It's okay to find things funny – you're laughing at the absurdity of the situation, not the person you love. And if you're angry, go into another room and punch a cushion. It's okay to be angry at the situation. Get your feelings out.

People have said to me that I'm coping well with it all, but of course it has been hard at times. I think we're lucky that my mum is happy and content in herself. The truth is that you don't know what you're going to do until you're in that situation.



More info

Find out more about the National Dementia Carers Action Network at www.alzscot.org/ndcan

Best laid plans? Planning for your future

As Rabbie Burns said: "The best laid schemes o' Mice an' Men gang aft a-gley" which translates as "the most carefully prepared plans often go wrong". But what if you fail to make any plans at all? At best, your wishes might not be carried out as you would have wanted. At worst, your family may be left with long drawn out, complicated and expensive legal issues to resolve.

One of the positive aspects of receiving a timely diagnosis of dementia is that it encourages people to start putting future plans in place. Indeed, forward planning is one of the key pillars in the post diagnostic support being delivered to anyone receiving a dementia diagnosis in Scotland – planning for future decision making and future care.

Here are some of the key issues that we should consider in planning how our finances will be managed if we lose capacity and how our assets will be passed on after our death.

For detailed information and advice on any of these matters, please consult a solicitor and/or a financial advisor.

Power of Attorney (PoA)

Many people believe that a close relative will be able to take over managing their finances if they become unable to do so themselves. That is not the case, unless they have legal authority to do so.

A PoA is a written document in which you give someone you trust the authority to make decisions about your property and financial affairs and/or decisions about your health and welfare. Many people combine the two sets of powers in a single document but you can keep the two separate if you have different attorneys in mind for the different types of decision.

For more information, contact the Office of the Public Guardian on 01324 678300; Email: opg@scotcourts.gov.uk or visit www.publicguardian-scotland.gov.uk

Top tip

It is a good idea to have at least one attorney from a younger generation (like a daughter, son or grandchild) who is more likely to live longer than your spouse or partner.



Writing a Will

A large percentage of Scots die without making a valid will. Apart from a reluctance to consider our inevitable death, there may be many reasons why people choose not to leave a will, including:

I don't have much to leave so I don't need to bother

Everyone has an estate of some kind. "Estate" in this case doesn't necessarily mean rolling acres of land – your belongings, car, flat, modest savings or your engagement ring all count towards your estate.

I'm only 40 so I've plenty of time to worry about that sort of thing

You never know what might be round the corner, so your age isn't really an excuse. You may also have young children whose interests need to be protected.

My partner/wife/husband/family will inherit everything anyway

Not necessarily. Laws around inheritance haven't really kept up with the times. If you're not married or in a civil partnership with your partner, they

will have to go to court to apply for a share of your estate if you die without a valid will. If you are separated, your estranged spouse or partner may have a claim on your estate, to the detriment of your children or other family members you wish to inherit.

Under Scots law, widowed spouses, civil partners, children and other descendants have a legal right to a fixed share of your moveable property (i.e. excluding land and buildings), whatever your will states, making it all the more important to get advice from a professional. Find a useful summary at www.care-advisor.org.uk/rights-inheritance

Top tip

Review your will every few years and definitely when there are changes such as marriage, divorce, new children or grandchildren, or if an executor dies.

Inheritance Tax and Trusts

You should think about protecting the assets you are passing on, while still complying with the law.

Inheritance Tax (IHT) may be due if your estate is worth more than £325,000 and is paid at the rate of 40% of any excess over the IHT limit, not on the whole value of the estate. This may be reduced to 36% if 10% or more of the estate is left to charity. For more information visit www.gov.uk/inheritance-tax/overview

Your solicitor can also advise you about a range of trusts which can offer tax advantages but which can also protect your assets and make provision for children and other family members in the future.

£210,000 funding for befriending services

Two projects run by Alzheimer Scotland have been awarded £210,000 funding from the Life Changes Trust to provide befriending services to people who have dementia.

The first project is Alzheimer Scotland's 'Forget Me Not' service, based in Glasgow. Forget Me Not was set up in 2008 to recruit and train volunteers to befriend people with dementia who are living in care homes or in long term hospital care.

The project provides people with dementia regular, consistent contact with a befriender, to give them companionship and to help improve their mental, physical and social well-being. Volunteers can also develop and gain in

confidence themselves, encouraging a greater understanding about dementia, well-being and social inclusion in their own wider communities.

The second Alzheimer Scotland project is a new volunteer Buddying scheme for people with dementia in Lanarkshire. 10,000 people with dementia live in Lanarkshire, which is 11% of all people with dementia in Scotland.

This funding will provide reminiscence therapy sessions from trained volunteer befrienders, to people at all stages of the dementia journey, within their own homes. The sessions can cover a broad range of reminiscence subjects, from sport and local heritage to working life

or cultural changes, and are tailored specifically to each individual. The therapy sessions can also support improvements in the well-being of people with dementia, with a positive effect on their confidence to make more connections outside the family unit.

Both projects were awarded £105,000, over five years.

'The therapy sessions can also support improvements in the well-being of people with dementia.'

Do you need a break?

For people and families living with dementia a break from the day-to-day challenges of life can be a welcome relief.

Our Creative Breaks grants give you the chance to apply for up to £300 towards creating an enjoyable experience. Working with Shared Care Scotland we're offering financial assistance to help people in Scotland with dementia, their family, friends and carers access a well-earned break.

The aim is to improve the well-being of carers and the people they care for by supporting the financial aspects behind a relaxing break, or activities and equipment that will help relieve the everyday stresses of supporting someone with a diagnosis of dementia.

Are you eligible for a Creative Breaks grant?

- Are you caring for someone with a diagnosis of dementia?
- Do you need a short break?
- Have you not had a short break in the past 12 months?

If you answered 'yes' to the above, you may be eligible to apply for a Creative Breaks grant.

The break could be a holiday, or it could help pay for a photography course, or getting someone in to help with the garden. It's up to you. What would make a difference to your family?

More info

Visit our website to check eligibility and download an application form.

www.alzscot.org/creativebreaks



www.flickr.com/photos/rowanbank



Memory Walks Scotland 2015

From Aberdeen to the Borders and Arran to Moray, 26 Memory Walks took place across Scotland this September to mark World Alzheimer's Month.

Nearly 3,000 people proudly sporting purple t-shirts could be seen stepping out in Scotland's towns and cities to raise funds for Alzheimer Scotland and show their solidarity for families living with dementia.

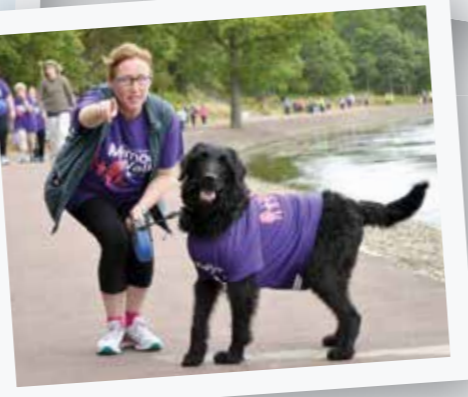
A huge thank you must go to all walkers and the people who sponsored them. Together we have raised nearly £160,000 and counting, making 2015 a record-breaking year for this popular family-friendly and dog-friendly event.

'Thank you for arranging these walks. It can really help deal with matters and lets us remember our loved ones.'

Julie Butler (pictured right) took part in the Milngavie Memory Walk to support her friends, whose father has Alzheimer's. She really enjoyed the experience, commenting: "What a great day! It was a bit emotional for a lot of walkers. I would love to do it all again. Thank you!"

This year we were pleased to receive support from Scottish actress Barbara Rafferty and sports commentator Alison Walker, who both have personal experience of dementia in their families. Their support helped Memory Walks to hit the headlines and attract more walkers.

The money raised at the walks will contribute to the running of Alzheimer Scotland services around the country, helping us to make sure nobody has to face dementia alone.



More info

To register your interest to take part in Memory Walks Scotland in 2016 go to www.alzscot.org/MW2016



Meet our pawsome new team member Buddy

This autumn saw a wonderful new addition to the Alzheimer Scotland team in the shape of a mascot, inspired by our real life dementia dogs.

Our furry friend came to us without a name and it was down to our supporters to meet the challenge of selecting an appropriate name. Hundreds of you took part in the naming competition at our Memory Walks and other events over the autumn. Thanks for your entries!

We can reveal the name of our mascot is... Buddy!

Well done to Andy Russell from Glasgow who submitted his winning entry at the Glasgow Memory Walk, where he was walking for his sister who has a dementia diagnosis.

Real-life dementia dog Alex-4-Paws

and owner Moira Whyte selected the winning name. Explaining her reasons for choosing the name Buddy, Moira said "I chose the name Buddy because for me that's what Alzheimer Scotland is all about. It's here so that you never have to be alone with dementia – you always have a friend, a buddy."

Look out for Buddy at Alzheimer Scotland events across the country and snap a selfie with our cute companion!

'Alzheimer Scotland is here so you always have a friend, a buddy.'



Make Alzheimer Scotland your business this year

Interested in supporting Alzheimer Scotland at your work but not sure how? Take some inspiration from our amazing corporate partners and have fun supporting Alzheimer Scotland with your colleagues. Here are just a few of the wonderful and sometimes wacky things they did for us in 2015!



Staff from the Scotmid Co-operative family have been racing towards their £250,000 Charity of the Year fundraising goal.

You could

Challenge yourself and your staff to do something active.

In Scotland we're lucky to have lots of iconic sporting events such as the Great Scottish Run and Edinburgh Marathon on our doorstep, but two of our partners really took their challenges to new heights (or depths) in 2015...Kames Capital raised a whopping £11,500 from a sponsored abseil, and three very brave members of staff from the Real Mary King's Close braved a sponsored shark dive! Think your office adrenaline junkies would like something similar? Get in touch with us on the details below.

Turn an old fundraiser on its head and put the fun back into fundraising.

Our partners at Toshiba Medical Visualisation Systems Europe put their imaginations to the test when thinking

of fundraisers for their office where casual dress is the norm. Instead of a dress down Friday they chose to do 'Formalities for Charities' where staff come in in their best evening wear!

Throw a Ball and increase your employee morale.

Gala events are a fabulous way of raising funds for Alzheimer Scotland as well as giving your staff and suppliers a great night out! We are partnered with the Rangers Charitable Foundation this year and they held a themed 'Putting on the Ritz' Ball in November which raised a whopping £100k for their chosen charities!

Think further than your staff.

We've had a really rewarding partnership with Wheatley Group over the last year, which has been strongly supported by the tenants in their social

housing complexes. From knitting blankets, baking cakes and making earrings, Wheatley Group tenants have been busy raising money and awareness for Alzheimer Scotland.

Utilise your suppliers.

Another successful partnership this year has been with Lend Lease who have held large-scale events for us throughout the year, including a hugely successful Golf Day which raised over £14,000 for their chosen charities! By encouraging your suppliers to get involved in fundraising you can raise even more money for your chosen cause as well as making others outside your organisation more dementia aware.

Take part in one of our ready-made fundraisers.

Our newest strategic partner HSBC took on our flagship fundraiser Tea &

Talk during the festive period. By baking cakes, having 'Memory Trees' in their branches and encouraging discussion around dementia and where to find support. HSBC will be raising vital funds and awareness throughout 2016.

Encourage your staff to take part in fundraising on a national level.

Since September our main Charity of the Year partners at the Scotmid Co-operative family have been raising funds on a national scale across their stores and offices through a wide range of activity, including a Christmas Hamper Raffle, sponsored store challenges and pin badge sales. In October, Lloyds Pharmacy took to social media to show us and their customers what they were up to with their themed spooky fundraisers! By having head office support, staff in these organisations

were able to hold fundraising events at their sites all across the country making a bigger splash for the charity.

Encourage your staff to get creative.

You could hold a Handbag Swapping event like our partners BAM Construction and charge a £5 donation per bag sold or create a bespoke charity calendar for sale like our partners at SELEX ES.

Supporting Alzheimer Scotland enables us to work towards our mission that nobody in Scotland faces dementia alone. Our corporate partnerships team can work with you to create a calendar of fundraising and awareness raising that suits your business, work force and customer base.

More info

For more information on how you can support us and how we can work with you to achieve your corporate social responsibility goals please contact the Corporate Partnerships team on: corporatefundraising@alzscot.org or 0131 243 1453.

Staff from Kames Capital are happy to be back on solid ground after their Forth Rail Bridge abseil.



Winter fundraisers



From Aberdeen to St Boswells, Renfrew to Edinburgh, the end of 2015 saw the red carpets rolled out and fancy frocks dusted off.

Thanks to party-goers across Scotland these gala events raised tens of thousands of pounds for Alzheimer Scotland. Here are some of the highlights from the party season...

The celebrations kicked off on 26 September with the Red Carpet Event in Aberdeen, which was organised by supporters Andrea Muirhead and Marie Milne. Nearly 200 of Aberdeen's finest turned out to support the event which was hosted by Edward Reid, of Britain's Got Talent, with entertainment provided by X Factor finalist Nicholas McDonald. The event raised over £7,000 for Alzheimer Scotland.

On 17 October, Glasgow's glitterati turned out in force for the annual Forget-Me-Not ball. It was a fabulous evening of singing, dancing, fundraising and fun. Entertaining the crowds were Steve McKenna (and his impressive tartan suit!) and The Singer Swingers. The ball raised a fantastic £13,150.

Sports fans turned out to support our sporting reminiscence projects at the annual Sports Dinner at Hampden Park

on 23 October. The evening was hosted by Lorraine Herbison, Head of News and Sport at Bauer Radio Scotland and included a guest appearance by everyone's favourite pundit Chick Young. Congratulations to everyone who raised over £20,300.

'Thanks to party-goers across Scotland these gala events raised tens of thousands of pounds for Alzheimer Scotland.'

Supporters in the Borders had a hootenanny at the Borders Forget-Me-Not-Ball on 21 November. Supporters turned out for a fun filled night of wild dancing, good music and great company. The Bedlam Ceilidh Band provided the tunes and altogether they raised over £1,600.

In Renfrew, former River City star Tom Urie and friends got us in the mood for Christmas at a fabulous Festive Friends evening on 13 November. The cosy event was attended by 65 people and they enjoyed live music, Christmas



shopping and a three course meal. This successful event raised **£3,220**.

In the capital, the Crystal Ball Held at Edinburgh's prestigious Prestonfield House Hotel on 28 November attracted 300 party-goers ready to bid on top auction prizes in aid of Alzheimer Scotland. The event, organised by Gavin Hughes and his team at Prestonfield, raised a super £32,000.

A huge thanks to everyone who bought tickets for these events and splashed out on buying raffle tickets and bidding in auctions. Thanks to the people who organised the events and to those who donated their time and prizes. All of you have helped raise vital funds for Alzheimer Scotland.



Make every penny count in 2016

The start of a new year is traditionally a time for new resolutions. Why not resolve to help Alzheimer Scotland raise the £15,000 we need every day to fund our vital services across Scotland?

There are so many ways to help raise money and it doesn't have to be difficult or time consuming. If you are looking for an easy way to help make a difference our Home Money Boxes are a great place to start. If every member of Alzheimer Scotland filled their box with just £10 in small change, this would mean an extra £75,000 to spend on making sure nobody faces dementia alone. Members have received a Home Money Box with this issue of 'Dementia in Scotland'; if you are not a Member, or would like extra boxes, call us on 0131 243 1453.

Another way of raising funds is to place collecting cans in local shops and community facilities. If you can place some cans, perhaps with local businesses or in your own workplace, then please contact us to request these and your guide to banking the funds. You can email us at fundraising@alzscot.org or call 0131 243 1453.

Our supporters have arranged a host of events and fundraising activities in their local communities. If you would like to get involved there is a range of ideas, resources and information at our Fundraising Toolkit at my.alzscot.org.

Once you have filled your Home Money Box, there are lots of ways you can get the money to us:

- **Post** – send a cheque for the amount to Home Money Box Appeal, Alzheimer Scotland, 22 Drumsheugh Gardens, Edinburgh, EH3 7RN
- **Online** – on our website at www.alzscot.org/donate or through JustGiving www.justgiving.com/alzscot
- **Telephone** – call 0131 243 1453 to pay with your credit or debit card
- **In person** – pop in to your local services or Dementia Resource Centre and let the staff know it's from the Home Money Box Appeal



Our network of Community Fundraisers can support you with advice and resources and you can find your local Community Fundraiser by visiting www.alzscot.org/communityfundraiser.

We need fundraised income to pay for vital services like our Dementia Advisors, Dementia Nurses, Dementia Helpline, Dementia Resource Centres and our Dementia Research Centre. Every penny you can raise will be used to help us reach more people with dementia and their families.



Celebrating autumn and winter fundraising



This brilliant golf day at Cawder Golf Club in Bishopbriggs was the latest in a long line of fundraising events organised by supporter extraordinaire and Alzheimer Scotland Ambassador, Dougie McCluskey. This event raised a smashing £2734. A big thank you to Dougie and his friends.



This Christmas our Edinburgh Dementia Advisor Teresa Straczynski raised £126 wrapping presents in Cameron Toll shopping centre along with members of the Alzheimer Scotland Edinburgh branch.



Four childhood friends, Rob, Craig, James and Jamie AKA 'The Purple Cobras' took on the mammoth challenge of climbing Mount Kilimanjaro this September. They raised an incredible £18,300, smashing their target of £12,000.



This September, Crossmichael Events Triathlon raised more than £6,000 for three charities, including Alzheimer Scotland. We received a kind donation of £1550. Jim McLelland one of the organisers explained "my first wife had cancer and my dad had Alzheimer's but these are things that touch everybody so it was nice to collect money for these causes."



This summer the Rotary Club of Dingwall held their annual Wade Walk and Alzheimer Scotland was the main beneficiary of the fundraising. 88 people took part in the 15 mile challenge and raised a fantastic £2000 towards the opening of our Dementia Resource Centre in Dingwall. A great big thank you to all the walkers!



Suraya Ahmed and her fabulous dancers were joined by Pulse Radio DJ Andy Coyle for a dance extravaganza called 'When east meets west' showcasing a variety of dance and music at Eastwood Park Theatre. They raised £1,300!!!



Mother and daughter team Marion and Sarah Murdoch cycled from London to Paris this summer, raising an incredible £3,350 for the new Helensburgh Dementia Resource Centre. They've since had matching tattoos to remember their efforts!!!

Dates for your diary

Whether you are interested in dancing the night away, taking part in a 5k run, listening to some excellent music, or attending a conference, there is an event coming up to suit you over the next few months. Visit our website www.alzscot.org for more information or call our Events Hotline on **0131 243 1453** if you would like to know more about any of our physical fundraising events.

March

Sat 12 March

Mighty Deer Stalker Obstacle Course
[Innerleithen]

Sun 20 March

Kilomathon [Edinburgh]

April

Sat 2 April

Zipslide Across the Clyde

Sun 17 April

Great Edinburgh Run [10 miles]

Sat 23 April

Ladies Lunch, Glasgow

Sun 24 April

London Marathon

May

Sat 14 May

Wigtownshire Sparkle Ball

Sun 15 May

Aberdeen Baker Hughes 10k

28-29 May

Edinburgh Marathon Festival

June

Mon 30 May –

Sun 5 June

Fri 3 June

Dementia Awareness Week 2016

Sun 5 June

18-19 June

Sat 25 June

Alzheimer Scotland Dementia Awareness Week Conference

Great Women's 10k Glasgow

Edinburgh Night Ride [50 miles]

Tough Mudder [Drumlanrig

Castle, Thornhill]

Forth Rail Bridge Abseil

Sun 26 June

July

1-3 July

Sat 23 July

Sun 24 July

West Highland Way trek

Spartan Sprint Edinburgh [5k]

Spartan Beast Edinburgh [20k]



Save the date!

Alzheimer Scotland Dementia Awareness Week Conference 2016



Friday 3rd June Edinburgh International Conference Centre

“Global to local: research, practice, innovation”

Join us for Scotland's leading dementia conference. Find out more at www.alzscot.org/conference16