



Dementia in Scotland



Inside - special feature on Dementia Demonstrator Sites



Pioneering
best practice in
dementia care



SDWG
celebrates
10th birthday



New guide for
proxy decision
makers
launched

Chief Executive's **comment**



I am sure most of our readers will know that, in June, Alzheimer Scotland won the prestigious award of SCVO Charity of the Year 2012. This is a remarkable achievement when you look at the calibre of the other shortlisted organisations. This recognition is something that every person connected with Alzheimer Scotland has played a part in and should be very proud of. It has taken many decades of committed campaigning and service provision by all our members, staff and volunteers, past and present, to achieve the recognition and respect for our efforts that we are currently enjoying.

Our mission is to make sure that no-one, anywhere in Scotland, goes through dementia on their own and we certainly cannot achieve this by ourselves. There are, quite literally, thousands of people supporting this mission each and every day. We have many partners, both organisations and individuals, who make this possible, and we have the support of the Scottish public and businesses who help us by raising the vital

funds that allow us to make such a significant contribution to the lives of people with dementia and our local communities. Without this support we simply could not survive and I want to take this opportunity to express my thanks to all of you who make and have made Alzheimer Scotland the organisation it is today.

In the last edition of Dementia in Scotland we focused on the announcement of the new Post Diagnostic Support Guarantee by the Deputy First Minister, Nicola Sturgeon. This is one of the key priority areas of the National Dementia Strategy and we were very pleased that the Scottish Government's commitment included using our Five Pillars of Post Diagnostic Support Model.

In this edition we are focusing on another key element of the strategy, the three Dementia Demonstrator Sites. These sites are responsible for looking at how we can make best use of current investments in dementia care and are exploring how to redesign and reshape the whole system to improve outcomes for people with dementia and their carers. We look forward to the key lessons being shared from this and used across Scotland.

Of course, we have our own views of how the health and social care system needs to change and improve overall for people with dementia and their carers. That is why we have just released our new policy report "Delivering Integrated Dementia Care – the 8 Pillars Model of Community Support". This report uses the best evidence to offer a new way of thinking about support for people

with dementia currently living at home whose needs are such that they need both health and social care intervention, and presents a new model for how we believe this should be provided. We hope to gather as much support for this model as possible and would very much like to see it become a priority area for the next Dementia Strategy in 2013.

This month also sees the first National Dementia Awards, which we have developed in partnership with NHS Education Scotland, NHS Health Scotland and the Scottish Social Services Council. We received just under 130 applications for these awards, which is remarkable. It is so very reassuring to see how many first-class initiatives and interventions are being developed and implemented in Scotland. There is no doubt we have all the right ingredients of successful dementia care dotted around Scotland; we just need to bring them all together in every area and every locality and ensure that every person living with dementia has equal access to these wonderful and highly personalised standards of practice. We hope that these new awards will be a great celebration of such successful work and will be an inspiring opportunity to share and learn from some of the best practice taking place in Scotland.

Henry Simmons
Chief Executive, Alzheimer Scotland

Scottish Charity of the Year success



L to R: John Swinney MSP and Cabinet Secretary for Finance, Employment and Sustainable Growth, Henry Simmons, Chief Executive and John Laurie, Convener, Alzheimer Scotland, and Ken Pennykid from award sponsors Keegan & Pennykid.

Alzheimer Scotland was delighted to have won the Charity of the Year award at SCVO's Scottish Charity Awards 2012, held in Glasgow's Old Fruitmarket on 14 June. The award is a recognition of many years of dedicated effort towards improving the lives of people with dementia, their carers, partners and families.

Henry Simmons, Chief Executive of Alzheimer Scotland, said, "I would like to say how delighted we are to win this prestigious award. We have only been able to achieve such strong progress thanks to the thousands of people who support us, the dedication and hard work of all our staff and volunteers, and to the positive and supportive partnerships with key policy makers at all levels.

"We dedicate this award to all the people with dementia, and their partners, families and carers whom we support and who support us. Together we can make sure that no-one goes through dementia on their own."

Cover picture shows Henry Simmons accepting the Scottish Charity of the Year award. In background, L to R, Convener John Laurie, Ken Pennykid and SCVO Convener Dr Alison Elliot

Dementia Resource Centre opens in Highland

Alzheimer Scotland has officially opened its brand new Highland Dementia Resource Centre at 2 Strothers Lane in Inverness, conveniently located between the bus station and train station. The launch was attended by key representatives from NHS Highland and Highland Council, as well as high profile dementia awareness activists Nancy McAdam (a member of the Scottish Dementia Working Group) and Ann Pascoe (from Alzheimer Scotland's National Dementia Carers Action Network).

Linking in with our local Dementia Advisors, Dementia Link Workers and our network of services across the Highlands (including specialist day care service at Woodlands), the Resource Centre will be a source of information and advice, while also promoting early diagnostic care and support. It will offer the potential for dementia specific drop-in sessions, activities and interest groups, as well as carer groups and information on dementia-specific personalised support services.



Our proud Highland team outside the new Dementia Resource Centre

The Resource Centre has also had its first high profile visitor in Minister for Public Health, Michael Matheson MSP in a recent trip to the Highlands.

Scottish Dementia Working Group celebrates 10th birthday



Agnes Houston, Chair, SDWG addresses guests. Photo: Chris Watt Photography.

The SDWG celebrated this milestone in style with a reception in June at the National Gallery in Edinburgh, hosted by the Scottish Government. 100 guests, including around 40 SDWG members, attended the celebration alongside family and friends and people who have supported the Group at various points through the past decade. Deputy First Minister Nicola Sturgeon praised the work of the group and highlighted the importance of the voice of people with dementia influencing policy.

The next Scottish Dementia Working Group AGM will take place in Perth on 15 November and will give members a further chance to mark their 10th anniversary. The Group is recording messages of congratulation in a Birthday Book – if you wish to send a handwritten note to be added to the book, please address it to Deborah Grossman or Shona Paxton, Alzheimer Scotland, 81 Oxford Street, Glasgow G5 9EP by 31 October at the latest.

Dementia: making decisions – new guide launched by Deputy First Minister



With Nicola Sturgeon and Jan Killeen (striped top) are (L to R) Rose Mary Bowes (member of the reference group for the guide), Carolyn Brown and Ann Pascoe, all members of the National Dementia Carers Action Network.

This practical guide aims to help family members, partners and friends who have powers of attorney or guardianship to make decisions on behalf of a person with dementia, or who are thinking of taking on this responsibility.

Nicola Sturgeon, Deputy First Minister, Cabinet Secretary for Health and Wellbeing welcomed the guide at the launch on 26 June at the Festival Theatre, Edinburgh saying:

“The Adults with Incapacity (Scotland) Act 2000 sets out the arrangements for powers of attorney, and for intervention and guardianship orders. Those who act as legal proxies under the Act need to have confidence that they are acting in the best interests of the adult. While the provisions of the 2000 Act covers adults who lack capacity from whatever cause, adults with dementia form the majority, and so it is extremely helpful to have their particular situation covered in this guidance”.

This easy to read guide is free of charge and has been published as part of project funded by the Nuffield Foundation. Jan Killeen,

recently retired Director of Policy, led the research and wrote the guide which was informed by the experiences of family members across Scotland who volunteered to take part in discussion groups and interviews. The study found that few carers knew about the principles or rules within the Adults with Incapacity (Scotland) Act they are required to follow.

The guide shows how the principles can be used to aid good decision-making for the person with dementia. It also helps attorneys and guardians to find practical ways through difficulties in dealing with bureaucracy, professional differences and family conflicts and provides signposts to finding specialist help.

In addition to a guide, carers in the study said that they would have welcomed the opportunity to attend a short training course before or soon after taking on the duties, and to be part of a peer support group with other lay proxies caring for someone with dementia. They also wanted access to a non-legal expert on the Act if problems arose.

Key messages from family member attorneys and guardians

Find out all you can, its hard work, it takes time – but do it!

Use your powers, negotiate what you want for the person

Know your rights and the rights of the person

Keep asking questions

Don't feel guilty – you are doing your best

Seek help – you are not alone

Give yourself a break – you need to survive

The study found a greater awareness of the need for training and support for lay attorneys in some US states, in The Netherlands, Germany and Austria, with some initiatives taking place in these countries. In roundtable discussions with key stakeholder groups in the UK there was agreement with the issues raised by carers and a concern to find solutions. A 'Research summary and recommendations for policy and practice' was also launched with the guide.

The Guide and Research Summary report are both available to download on the Alzheimer Scotland website at: www.alzscot.org/decisions or hard copies on request to e-mail: info@alzscot.org or telephone the Freephone 24hr Dementia Helpline 0808 808 3000. For further information about powers of attorney or guardianship contact the Dementia Helpline.

Dementia demonstrator sites – pioneering best practice in dementia care across Scotland

Introduction

Scotland's National Dementia Strategy, published in 2010, set out key priorities for improving the delivery of care to people with dementia, their families and carers. The strategy recommended that 'care pathways' – the journey that people with dementia take through the health and social care system – should be comprehensively reviewed and redesigned where necessary.

Because different aspects of dementia care are often provided independently by health boards and local authorities, care pathways are not always optimal. To address this, the strategy recommended 'transformational change across the health and care system that goes beyond changes to parts of the system'. It emphasised that care for people with dementia should include coordinated input from the third sector and independent providers, recognising the critical role they play in working in partnership with local authorities and health boards.

The Scottish Government's Quality and Efficiency Support Team (QuEST) and Joint Improvement Team are currently supporting three pilot projects enabling NHS boards and local authorities to redesign their dementia care pathways in an integrated way, in partnership with the third sector and independent providers. These partners include Alzheimer Scotland and the Scottish Dementia Working Group.

The three pilot sites – in Midlothian, North Lanarkshire and Tayside – are known as the 'dementia demonstrator sites'. This article looks at some of the novel approaches being introduced across the demonstrator sites, and describes some of the findings so far.

Understanding the approach

Redesigning services has the potential to significantly improve standards of care while also freeing

up resources. Key elements include avoiding duplication and providing better preventative care.



Ruth Glassborow, National Lead for Mental Health at the Scottish Government's Quality and Efficiency Support Team, is coordinating the demonstrator sites project at a national level. She explains that "Our overall aim is to develop better outcomes for more people for the same or less resource". If this seems optimistic, Ruth adds "We believe this is possible because we constantly hear examples about health and social care services responding too late or in the wrong way. This means we miss opportunities to work with individuals to support them to remain independent for longer. Or, in the case of admission to general hospitals, we end up disabling people because our system isn't set up to respond appropriately to individuals with dementia.

"We need to redesign our services so we give people what they need, when they need it and do it right the first time. We are not saying that in the longer term we won't need more investment in dementia services, just that we can do so much more with what we currently have".

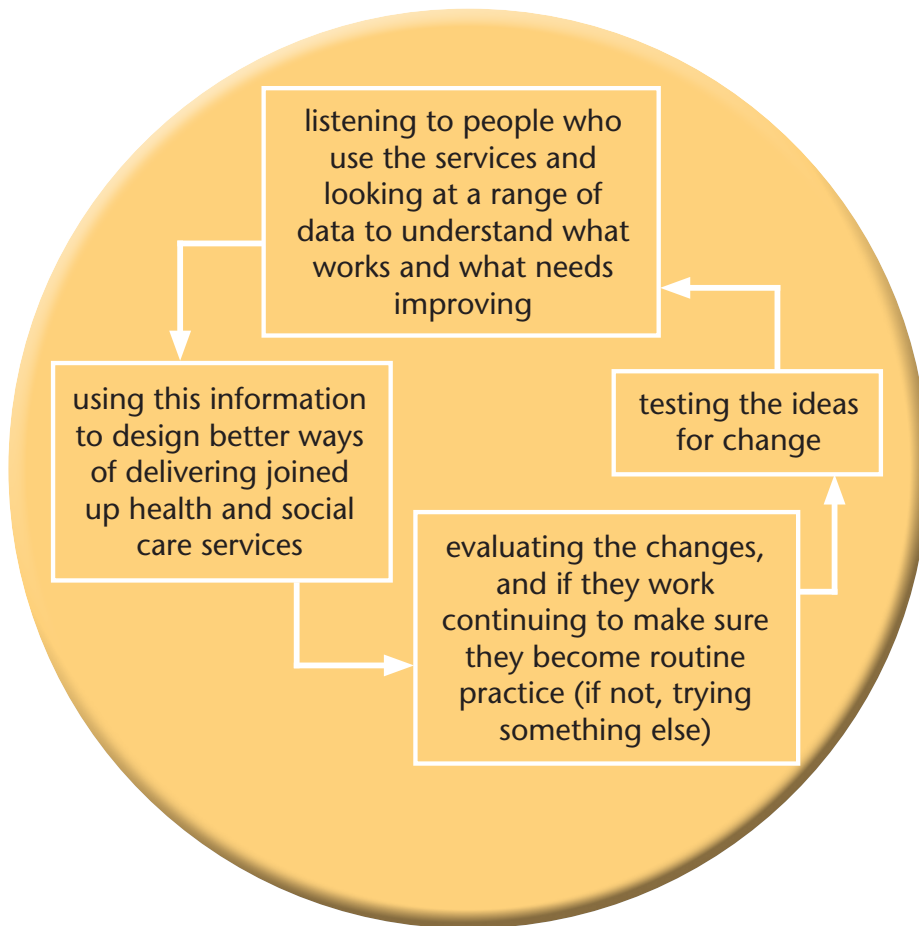
The three demonstrator sites are within community health partnerships (CHPs), which were themselves established to facilitate closer working between health boards and local authorities. Each site is using a structured approach to evaluate its existing services and test out alternatives. This is based on the following cycle:

Piloting the work

Three pilot sites were chosen across Scotland that provided a range of different demographic and geographical features. The pilots formally started in early 2011 and were initially intended to run for 15 months. However, earlier this year they were extended for a further 15 months, enabling them to build on progress to date and providing more time for evaluations to be carried out. The aim is to illustrate how the sites have demonstrated they can provide better outcomes for more people with the same or less resource by redesigning care pathways across the whole system.

Although each of the three sites has focused on local priorities, several common themes emerged relatively early on. These include:

- redesign of pathways to enable earlier diagnosis
- better post-diagnostic support
- care at home services which maximise independence
- a focus on reducing unnecessary admissions to acute hospital settings and care homes and improving the quality of care for those who do need admission
- ensuring that staff are up-skilled as necessary
- ensuring that families and unpaid carers are treated as equal partners in care.



Different approaches are being trialled across the different sites, reflecting local priorities and enabling a wide range of new ideas to be tested. During the pilot process, learning is being shared between the three sites, as well as being used to make policy changes at a national level. To help spread the results more widely, presentations hosted on the web have been scheduled, enabling services across Scotland to hear about what is taking place in the demonstrator sites (see 'Sharing the knowledge', below). A website is also being constructed and will be used to publish findings.

In addition to work linked to the three specific localities, the Joint Improvement Team (JIT) is supporting a range of initiatives that relate to housing for people with dementia. This acknowledges the recommendations of Scotland's national housing strategy for older people, *Age, Home and Community*, which recognised the need for improvement in housing and housing services.

There are a number of ways that housing links into the service redesign advocated by the dementia demonstrator site work. For example, if housing staff are provided with appropriate training, they may be able to signpost people with undiagnosed dementia to health and care services. Similarly, a range of affordable technology is now available that can enable people to live independently at home for longer. Helping housing providers understand and publicise what is available can potentially benefit people with dementia who may otherwise lose their independence and require expensive residential care.

Perth & Kinross CHP



Work taking place across Perth & Kinross CHP for the dementia demonstrator project has led to the development of the **Strathmore Dementia Service (SDS)**. Stimulated by the closure of an under-utilised admission ward in Blairgowrie, new community-based services were introduced. As a result the existing Older People's Mental Health Team has been expanded, with significant additional capacity created in the community to support people living with dementia and their carers. There is now a single phone number for accessing health services, and opening hours have more than doubled from 35 to 84 hours a week (8.30am to 8.30pm daily).

Examples of new initiatives have included an open-access memory assessment clinic, enabling members of the public with concerns about memory problems to ask for an assessment without being referred by their GP. The new clinic has led to some exciting results:

- many of those who attend had not previously discussed their problems with a GP and half of those surveyed said they wouldn't have attended if a GP appointment had been necessary first

- as a result the clinic has discovered 'hidden dementia', with diagnosis occurring earlier than via the GP route
- the service is reaching additional people. 250 were assessed during the first year, around four times the number assessed through GP referrals
- they presented about 18 months earlier in the course of their illness compared with the traditional GP route.

As well as increasing diagnosis rates and enabling diagnosis to take place earlier, the Strathmore Dementia Service has achieved several other successes. Psychiatric hospital admissions have been reduced by over 75% with no corresponding increase in care home admissions. Levels of antipsychotic prescription have also dropped.



Ralph Pogson, Cathy Robertson, Margaret Heron and Charles Yates. This photo was taken at the Scottish Dementia Working Group 10th birthday reception. Our nurses were instrumental in supporting them in becoming members of the SDWG and also sometimes supporting them to attend meetings.

The Strathmore Dementia Service has also introduced enhanced community support services for people with dementia, helping them to remain independent. The service provides information, advice and support for reablement, planning for the future and normalisation. If required, additional support can be offered through community support workers whose remit is jointly agreed with the person and their family. For example, the community support worker may go with the person to GP/hospital appointments, support them to go shopping or attend social activities

with them. One particularly useful aspect for many people is being supported when they go shopping. This support can assist them to maintain their own social networks and contacts.

"Although I've been given a diagnosis I'm still getting on with my life. You've hit it just right – The amount of support you are giving me. Keeping an eye on me but not interfering with my life".

Community-based support includes helping people during crisis situations. During the first 15 months of the project, staff supported 42 people during a crisis, with no episode resulting in admission to hospital or a care home. In addition, training has been provided to the 11 care homes in Strathmore, with a care home liaison service offering

information, advice, education and training. Additional support is available if a resident experiences a crisis.

The Strathmore Dementia Service aims to anticipate and meet the needs of people with dementia from diagnosis onwards, providing holistic support throughout the disease pathway. During the first part of the pilot there was an emphasis on health services. The next step is to improve coordinated care by enhancing partnership working with other agencies to optimise the care pathway.

Midlothian CHP



The changes being implemented across Midlothian's dementia demonstrator site are underpinned by detailed research into the views of staff, people with dementia and carers. A central element of this research has been the commissioning of a detailed narrative study, prepared by research staff at Queen Margaret University, to:

- develop a deeper understanding of what it means, and what it feels like, to live with dementia
- evaluate services provided to people with dementia and their carers in Midlothian
- build evidence to underpin the redesign of services provided to people with dementia and their unpaid carers.

The research was completed in April and links directly to the Standards of Care for Dementia in Scotland. It puts people with dementia and their carers at the centre of service redesign by tapping into their first-hand knowledge and experience of dementia.

Two specific elements of service redesign are now underway based on the findings of the study. These are a **family group conferencing** project, and the development and introduction of a **single dementia service**. This is designed around an integrated multidisciplinary team whose work will be aligned to the local Dementia Integrated Care Pathway, providing support from pre-diagnosis through to end-of-life and supported by a single assessment tool and care plan.

"The staff [at the rehabilitation hospital] are absolutely amazing and you visit and you can come home and you know that he's well looked after".

Midlothian's ongoing work to reduce the use of residential care and increase care at home

for all older people supports the dementia demonstrator site work. To further enhance this and minimise unnecessary admissions to acute hospital, an anticipatory care plan is being piloted with a local GP practice. To support those people with dementia who do need hospital treatment, training is planned to equip the community health practitioners and the hospital in-reach team as dementia champions.

"If I was to be honest with you, over the last few years I really couldn't ask for more help than has been given. Everybody has been really attentive."

Midlothian recently appointed a link worker and local area coordinator whose roles are to improve post-diagnostic support. As soon as a person is diagnosed with dementia, they are referred to the link worker who can signpost them to additional sources of support. They can also provide information on dementia itself, reflecting a finding that at the time of diagnosis patients often struggle to absorb all the information provided by healthcare professionals. Support from the link worker is available for a year following diagnosis.

The role of the local area coordinator is to help people with dementia access things to do during the day and prevent the risk of social isolation, either through a befriending service or by connecting people with dementia to groups or people in their community with similar interests.

Family group conferencing

A particularly innovative project taking place in Midlothian is the use of family group conferencing as a way of empowering family members to make decisions about the care of their relatives. Family group conferencing was developed in New Zealand in the late 1980s and acknowledges the rights of families to make their own plans regarding their family members. Although widely used in the UK, it

is most typically used to help make decisions about the care of children, rather than adults. This is the first time family group conferencing has been used with people with dementia and their families.

As the number of people being diagnosed with dementia continues to outstrip increases in resources, there is a universal acknowledgement that more care must be provided for less money. Midlothian is exploring how family group conferencing can be used to provide better support in the community more cost-effectively. Families are at the centre of the process and are supported by a coordinator who is independent of statutory bodies. They provide information to the family, then step back, ensuring that conclusions are reached by the family themselves, hence ensuring they have a sense of ownership.

Family group conferencing acknowledges that traditional support networks are often sidelined as an unforeseen consequence of high levels of professional support. It uses a broad definition of family to include 'families of connection', not just blood relatives. The model being applied in Midlothian aims to:

- share decision-making and planning with the person's extended support network, empowering them as a group to make the best possible decisions for the person with dementia
- ensure that the views and wishes of the person with dementia are heard (if possible) and taken into account
- reduce and delay for as long as possible the need for formalised interventions and services
- enhance the likelihood of coordinated care and support within the family network
- enhance partnership working between families and professionals.

North Lanarkshire CHP



Work undertaken across North Lanarkshire CHP as part of the dementia demonstrator site has included:

- piloting improvements in post-diagnostic support, drawing on the 'Five Pillars of Support' model developed by Alzheimer Scotland
- providing outreach from existing integrated day services which can assist in the avoidance of unnecessary acute hospital admissions
- building a dementia friendly community in Motherwell
- supporting the development of dementia cafes and innovative and intergenerational reminiscence activities
- developing staff skills, including the skills of those working in the housing sector
- developing an Integrated Care Pathway for Palliative Care in Dementia
- improving awareness and information in acute hospital settings about the role of assistive technology and telecare in supporting people to remain safely and confidently in their own home.

A brief overview of some specific areas of the work being done is outlined below.

Dementia friendly communities

The dementia friendly communities initiative is helping to develop a supportive environment for people living with dementia, their families and carers in its broadest sense. It is based around Motherwell town centre where work is taking place with local businesses and services to enable them to respond to the needs of people with dementia better. The approach combines environmental improvements with education to reduce stigma and enhance understanding about how to respond to the needs of people with dementia.

As part of the initiative, individual stories about people's current experience have been gathered. Towards the end of the project, feedback will be sought to document any changes that have taken place. Developing dementia friendly communities is a long-term task that depends for its success on a cultural shift. Sustainability is being built into the initiative through active collaboration with Alzheimer Scotland and the Voice of Experience Forum.

Making Life Easier

Making Life Easier is a service provided through North Lanarkshire Council's website that enables people to find out how to manage everyday activities independently and safely. It offers information on a wide range of health matters, and uses self-assessment to suggest pieces of equipment that can make living at home easier. Making Life Easier is provided in partnership with the Integrated Equipment and Adaptations Service. Input from Allied Health Professions and Strathclyde Fire and Rescue has ensured the website is accessible and relevant for people worried about their memory or living with dementia, their families and carers. The software collects data on the number of people accessing the site and the nature and progress of their enquiry.

Dementia cafes

As part of the dementia demonstrator site project, dementia cafes are now operating in Motherwell, Airdrie and Cumbernauld. These provide information, education and advice on a variety of topics for people who are worried about their memory or who are living with dementia. Support is also available for carers and family members. In addition, the cafes provide a forum for peer support, which is widely recognised as a key form of post-diagnostic support.

The public's response to the cafes has been very positive, with about 100 people attending the monthly sessions. These are made up of a combination of new and returning attendees. Initial findings suggest that referrals to local memory services have increased since the cafes were introduced, indicating that people with concerns about their memory are being signposted for formal assessment via the cafes. A full evaluation report will be carried out in summer 2013 with a view to recommending a roll-out of the cafes to the remaining three localities in North Lanarkshire.

Acute care

Several change initiatives have been implemented that relate to the acute care sector, supported by the Improving Care Dementia Group, the Alzheimer Scotland Dementia Nurse Consultant and the dementia demonstrator site pilot. These include:

- supporting the Dementia Champions to embed improvements in standards of care for people with dementia in acute hospital settings
- making changes to specific wards in Monklands Hospital so they are more dementia friendly
- introducing educational programmes for staff that support the Promoting Excellence framework. These are being delivered in partnership with the University of West of Scotland, University of Stirling and Alzheimer Scotland.



Delighted members of the Community Mental Health Team, NHS Lanarkshire on winning an award at Scotland's Dementia Awards. The team won in the category for Best dementia friendly community initiative for their Motherwell Dementia Cafe.

Next stages

Lanarkshire CHP

'We officially launched our dementia friendly community initiative in Motherwell on World Alzheimer's Day (21 September). Between 15 and 20 shops and businesses were the first to sign their commitment plans describing how they will provide a better experience for people with dementia. Some very big names including Boots, Asda and Motherwell Football Club have already pledged support, along with several local businesses. There were senior representatives from Alzheimer Scotland, North Lanarkshire Council and NHS Lanarkshire at the event, along with the chair of the Scottish Dementia Working Group.

'We are also taking forward a "Football Memories" project for which we were very fortunate to receive funding for three years from Comic Relief. The work is

being carried out in partnership with Motherwell Football Club and Alzheimer Scotland. The project has appointed a volunteer coordinator and is recruiting additional volunteers to help fans with dementia who want to relive their football memories.

'Our "Steeling Back the Memories" project is working to create reminiscence walks that link to the history of Ravenscraig Steelworks. We are working with Motherwell College, Ravenscraig Regional Sports Facility and other partners to develop this. It will include high-tech elements such as quick response codes that people can scan with their smart phones to access information. Students from Motherwell College are helping to gather digital stories, making this a truly intergenerational project.

'The young onset dementia service is currently developing its post-diagnostic support response in

line with the Five Pillars of Support model. An evaluation of this will be included in our wider review of post-diagnostic support to ensure we are meeting new targets in this area. Providing quality services for people with young onset dementia is particularly important as dementia is not just a disease associated with older people.

‘Our NHS Lanarkshire acute work is centred on continuous quality improvement. We are currently working on a project that is looking at the links between care homes and acute hospitals using ‘Getting to Know Me’ as a means of making hospital admissions smoother. This will ensure that information about the person travels with them and is available to support person-centred care planning from the moment they are first admitted. The next stage will be to see how we can roll this model out more widely.’

Sandra Shafii, AHP Consultant in Dementia

Perth & Kinross CHP

In order to identify ways of developing its new initiatives further, the Strathmore Dementia Service organised a ‘rapid improvement event’ in July involving 45 participants. This brought together people with dementia and their carers, as well as staff working in health, housing and community care. Other contributors included members of the community capacity building team and a care home representative.

Audrey Ryman, Programme Manager, explains: ‘This event brought people with dementia and their carers together with representatives from the local authority, health board and the third and independent sectors. With their support, we have identified priorities for the next phase of our service redesign. Key themes that emerged included improving awareness of dementia and the benefits of early diagnosis, as well as the importance of highlighting the range of services that are available to help.

“Staff are excellent, attentive and always available. I have spoken to some friends/family from south of the border and they feel we are being provided with a ‘brilliant service’ ”

‘During the second phase of the project we will be working closely with our partners to carry out more memory assessments. This will enable us to proactively identify more people with cognitive impairment. We will also start rolling out Promoting Excellence Level 1 and Level 2 training across health, housing and community care, along with the independent and third sectors. Discussions are also underway with our partners about developing a one-stop-shop for information and support, which is something users and carers have indicated they would like.’

As part of the Strathmore Dementia Project’s interim evaluation, it commissioned five patient and carer ‘digital stories’. These looked at all aspects of being diagnosed with dementia and caring for a person with dementia. Copies of the digital stories are available by emailing audrey.ryman@nhs.net

Midlothian CHP

‘A key element of our ongoing work is developing a single health and social care service, which once again picks up on what people are telling us – that they want a one-stop-shop providing support and information from diagnosis to end-of-life care. This won’t necessarily be based on a traditional model, and elements such as post-diagnostic support can potentially be provided by the third sector, rather than statutory bodies.

‘We are currently mapping our processes and thinking about how to improve the quality of services for people with dementia and their carers. The new service will be based around the existing Midlothian integrated care pathway for dementia. This will ensure that what we are providing is aligned with agreed best practice for

supporting people with dementia. Over the coming months we are hoping to roll out our anticipatory care plan, which will be facilitated by the community-based link-worker and coordinator. We are looking forward to getting them fully established and integrating their work into our dementia care pathway.’

Rebecca Squirrell, Planning Manager, Community Care

Sharing the knowledge

A series of internet-based presentations (WebExs) have been scheduled to showcase the work of the dementia demonstrator sites. The first of these took place on 13 July, with Dr Peter Connolly talking about the open access memory clinic that has been introduced in Perth & Kinross. His presentation was preceded by a short overview of the three demonstrator sites by David Piggott of the JIT. Audrey Ryman concluded with a brief summary of other work taking place in Perth & Kinross. Future WebEx presentations will enable information about other aspects of the work taking place across the demonstration sites to be disseminated to service providers across Scotland.

Dementia dialogue events – have your say

Scotland's National Dementia Strategy was launched in June 2010 with the aim of ensuring the highest quality of care and support for people with dementia at every stage of the illness.

The Scottish Government is now reviewing the progress of the Dementia Strategy and will be launching an updated Dementia Strategy for Scotland, during 2013.

Alzheimer Scotland has organised six free Dementia dialogue events throughout Scotland as an opportunity for you to come along and comment on the progress of the strategy to date,

identify the gaps, opportunities and priorities and to help shape the direction of Scotland's National Dementia Strategy from 2013. If you have experience of dementia - as a person diagnosed, a family member, carer, or as a health, social care or housing professional - we welcome your views.

To book a place at any of these events, or to make an enquiry about an event, please e-mail externalevents@alzscot.org or call Shona Paxton on 0141 418 3936. Each event will run from 11:00 – 15:00 (registration and refreshments will be available from 10:30). Reasonable travel expenses

may be claimed by people with dementia and family carers.

Inverness – 29 October 2012
(book by 24 October) - Caledonian Stadium, Inverness

Fort William – 30 October 2012
(book by 24 October) - The Ben Nevis Hotel, Fort William

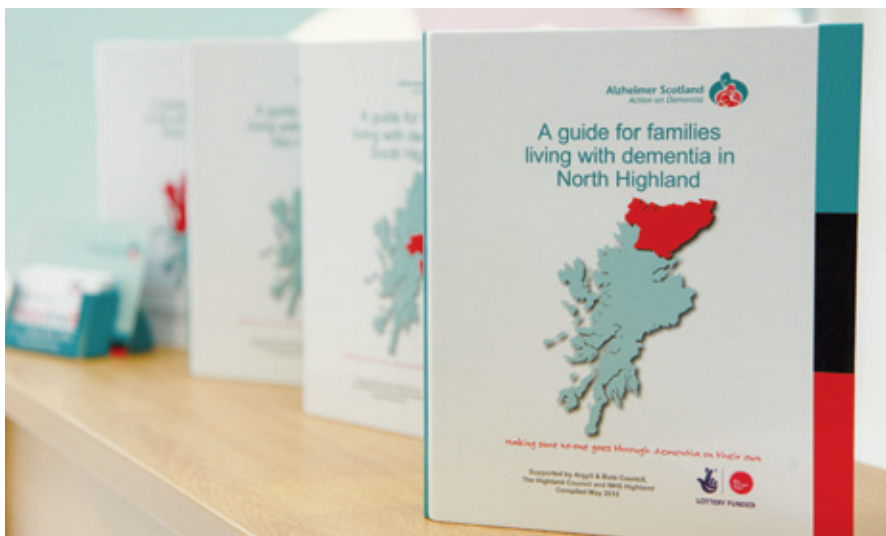
Dumfries – 7 November 2012
(book by 2 November) - Easterbrook Hall, The Crichton, Dumfries

Dundee – 22 November 2012
(book by 19 November) - Best Western Queens Hotel, Dundee

Bellshill – 3 December 2012
(book by 27 November) - Hilton Strathclyde Hotel, Bellshill

Paisley – 10 January 2013
(book by 7 January) - Glynhill Hotel, Paisley.

New Guides for Families in Argyll & Bute and Highland



As well as opening a new Dementia Resource Centre in Inverness (see page 3), our Highland and Argyll & Bute staff were delighted to launch a set of new resource guides for families supporting someone with dementia living in those areas.

The guides were developed as part of a research project, funded by the BIG Lottery Fund, which aimed to enhance support and information provision for carers and family members.

Each guide is made up of 3 sections:

Section 1 outlines important things for families to know and consider. It also provides details of where to find out more information.

Section 2 outlines staff you are likely to have contact with and what their roles are.

Section 3 lists what supports are available in your area for family carers and the person with dementia and how to access them.

There are four guides available for each area:

Highland
Mid Highland
North Highland
South Highland
West Highland

Order your free copy from:
Alzheimer Scotland Highland
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All four guides can also be downloaded from our website at <http://dementiascotland.org/news/2012/a-guide-for-families-living-with-dementia-in-argyll-bute-and-highland/>

Dementia Advisor Network grows

Our Dementia Advisor network now numbers 29, covering most local authority areas in Scotland. We have had a few changes of staff recently and welcome James McStay in South Lanarkshire (replacing Teeda Boyd); Iain Houston in Renfrewshire (replacing Fiona Gordon); Wilma MacDonald in North Ayrshire (replacing Vaughan Jones); Nadia Sutherland in Dundee; Julie Anne Moore in Falkirk (replacing Justine Davidson); and Kerry MacPhee in Stirling & Clackmannanshire (replacing Carole Pascal).



Most of our Dementia Advisors at a recent meeting in our new Dementia Resource Centre in Fife

Facing Dementia Together reaches final in Care Accolades

Care Accolades was launched in 2004 to celebrate and promote good practice in workforce development in social services across Scotland. A joint initiative by the Scottish Social Services Council (SSSC) and the Scottish Government, the Care Accolades 2012 rewards outstanding examples of excellent initiatives and projects within social services in Scotland.

The Facing Dementia Together post-diagnostic project in East Renfrewshire supports people who have recently had a diagnosis of early stage dementia and their families/supporters. After diagnosis, people often feel devastated, alone, confused about what the diagnosis means for their future and don't know where to turn to for help.

The project can help people to understand and come to terms with the diagnosis, develop coping skills, and access supports.



Post-Diagnostic Support Manager Tracy Gilmour (3rd from left) receiving the finalist certificate

We were delighted to be named as a finalist for this year's Care Accolades. Although we didn't win our category, getting through to the final shows the recognition of both the importance and value of post-diagnostic support and of the contribution that the project has made in developing a model of support that can be used across Scotland.

Counsellor Eileen retires after 18 years

We recently bade farewell to Eileen Gardner who has retired from her position as Counsellor with our Glasgow Younger Persons Support Service after 18 years with Alzheimer Scotland. Eileen was responsible for developing a unique service for people with a dementia, providing a one to one counselling service and developing and running self support groups.



Among her retirement gifts Eileen received a Kindle which she says she will treasure as she will now have more time to read for pleasure. We wish her all the best for a long, happy and healthy "retirement", although Eileen's skills will not be lost to Alzheimer Scotland completely as she will be working for us on a freelance basis.

We welcome Anne Davie as our new Counsellor in Glasgow.

The media have reported on a wide range of research over the summer – here is a summary of just a few of the key stories.

Bapineuzumab

This drug is a laboratory-produced antibody designed to target and bind to beta-amyloid, a protein that has toxic effects in the brain and is believed by many scientists to be a cause of Alzheimer's disease. There were high hopes for Bapineuzumab but it has proved ineffective in its first large scale clinical trial with no improvement identified in cognition or daily functioning in subjects receiving the drug compared with people receiving a placebo or dummy pill.



Solanezumab

Another antibody targeting beta amyloid, this drug showed failure in two phase 3 clinical trials in its main aims of preserving mental performance and functional abilities, although there was some slowing of cognitive decline in people with mild Alzheimer's disease.

The failure of these trials and others of drugs targeting beta amyloid have raised questions about whether this protein is really the cause of the problem in Alzheimer's disease. Other experts suggest that perhaps these drugs are being tried too late on in the development of the disease and that it would be better to prevent beta amyloid being formed in the first place rather than trying to get rid of it after it has formed.

Intravenous Immunoglobulin (IVIG)

This contains antibodies from blood donors and is normally used in the treatment of autoimmune diseases and serious infections. It is thought to work by clearing beta amyloid from the brain, allowing brain cells to function properly.

A lot of excitement was generated when this small scale study involving people with mild to moderate Alzheimer's disease was announced in July at the Alzheimer's Association international conference in Vancouver. In this Phase 2 trial, 12 people received the treatment and 12 a placebo for six months. Then all 24 received the treatment. The study found that people who took the same dose of IVIG every two weeks for 3 years had no decline in cognition, memory, daily

functioning or mood. There were also no significant adverse side effects. The people who began on a placebo or received different doses of IVIG saw a significant decline in these symptoms.

A larger phase 3 trial is now underway.

CAD 106 – new vaccine

This is being developed in Sweden where researchers have recently completed a small scale (58 subjects) human trial of a vaccine developed to trigger the body's immune system to fight beta amyloid. The study was designed to test whether the vaccine was safe to use in people before attempting the necessary larger scale trials. Earlier attempts by other researchers at producing a vaccine failed when some subjects developed inflammation in their brains. Side effects were experienced by 74% of people receiving the vaccine but this was mainly cold-like symptoms or a rash at the injection site.

Ginkgo biloba

A French study involving nearly 3,000 people and reported in the Lancet Neurology found that herbal remedy Ginkgo biloba does not significantly reduce older people's risk of developing Alzheimer's disease. After five years, 61 (four per cent) of people in the ginkgo biloba group had been diagnosed with Alzheimer's compared to 73 (five per cent) of people in the placebo group.

Dementia Community Roadshow **tours Shetland**



Angie Smith from our Fundraising Team and husband Paul flying the flag for Alzheimer Scotland, even on holiday!

The Dementia Community Roadshow aims to reach 10,000 people across Scotland by October 2014 via our latest mobile information vehicle which is funded through monies raised by our Tesco Charity of the Year partnership. We decided to take the Roadshow to the most remote Scottish Tesco store in Lerwick, Shetland Islands, combining our visit with a tour of other parts of Shetland and a local launch of the *Living well with dementia* DVD produced in partnership with NHS Health Scotland and the Scottish Dementia Working Group.

We were encouraged to make an early visit to Shetland as there is now a Dementia Advisor in post – Ann Williamson who is a native of Shetland – as well as a Dementia Clinical Nurse Specialist (Steve Mullay) and Dementia Services Development Manager (Alan

Murdoch). Our visit would also give an opportunity to let people know about these local sources of support for people with dementia and their families.

After a long (14 hours) and fortunately smooth crossing from Aberdeen, we arrived bright and early in Lerwick and made our way to Tesco to check on the set up for our afternoon opening. We soon discovered that we couldn't get our large vehicle into the car park at our hotel as the road was too narrow but the Health Board came to the rescue and allowed us to park behind their headquarters.

Later in the week we took the Roadshow to care centres in Walls and Unst, to the leisure centre in Mid-Yell and the health centre in Brae and a very wet and windy Dunrossness but the most picturesque setting was in

a car park overlooking the sea at Scalloway where we met up with local couple Marina and Ian Gray. Marina was due to speak at the DVD launch event later in the week and we kept running into each other throughout our stay.

Although we didn't see huge numbers of people during our stay (and we didn't expect to) I was struck by the real interest expressed by staff in the care centres we visited in extending their knowledge and receiving dementia-specific training. The issues raised by visitors were generally no different from those on the mainland but we heard how the challenges of getting specialist diagnosis were being overcome through the use of video-conferencing with a specialist consultant based in Aberdeen. It may be a cliché but as a city dweller it was fascinating to see how people seemed to know one another and how close-knit the community seemed. I just wish we'd had the time to visit the community owned shop at Bigton where they are receiving advice from Alan Murdoch on how to make the store dementia-friendly, looking at things like the layout and lighting as well as training needs of staff.

Since our visit, at least one person has been on the phone to our Dementia Helpline and several visitors have had follow up calls with our Dementia Advisor and support from Nurse Specialist Stephen Mullay. The tour, combined with the DVD launch and the excellent coverage of the Shetland Times will have gone a long way towards raising awareness of dementia in the Shetland Islands.

Maureen Thom
Information Manager, Alzheimer Scotland

Blanket world record **smashed!**



Pupils from St Joseph's Primary and ladies from Hawthorn Court with some of their handiwork

Alzheimer Scotland's hand-knitted blanket challenge began life as a local awareness-raising event but soon became a huge collaboration of knitters across Scotland, and indeed the globe. Offers of help (and submissions of knitted squares) started to flood in from the USA, Canada, Europe and all over the UK. Pupils from St Joseph's Primary School, Busby and residents of Hawthorn Court Sheltered Housing Complex in East Renfrewshire knitted over 12 blankets, with the residents teaching the pupils to knit in exchange for lessons in how to send texts! Local Alzheimer Scotland services across Scotland were overwhelmed and humbled by the passion and enthusiasm of thousands of knitters.

Here, Jean Armitage from our Helensburgh Dementia Resource Centre describes the day the new record was verified.

Our attempt to beat the record for the world's biggest blanket previously held by the Ladies of Hatfield Christian Church was not only successful, we also beat the target we had set ourselves, managing a staggering 914 square metres, almost double the previous record.

The world record was verified at an event in the grounds of Inveraray

Castle on 23 June. The challenge didn't end with the knitting – torrential rain meant we couldn't take the giant blanket out of the marquee to wrap it around the castle as planned and the closure of the main road to Inveraray led to a diversion of 25 miles to even get there in the first place.

The weather meant that the measuring and verification process had to take place in the marquee and took more than three hours rather than the 20-30 minutes it should have taken, due to space restrictions. Many thanks to our three verifiers who gave up their afternoon: Elaine Robertson who got stuck in as soon as she arrived and helped with the last bits of sewing, Mike MacKenzie, MSP and Tim Williams, surveyor who was not the least bit fazed by having to measure the blanket in such a small space! All three took their role very seriously, giving nothing away as they walked up and down measuring and checking every section.

We could not have managed this achievement without the help of many, many people: all those who knitted squares and complete blankets for us; those who helped us sew them into blankets; those who stored and delivered squares and blankets; and those who

helped spread the word and encouraged people to get involved.

A final thank you goes to Chris Doogan, who came up with this mad idea; I cannot wait to see how she tops this next year!



Ever wondered what 914 knitted blankets looks like?



Inventive knitter Christine Ross incorporated an Alzheimer Scotland logo into a blanket

We are offering a unique opportunity for you to make your own stitch in this special blanket by buying a 'virtual' square: a donation of £2 to represent the hard work, fond memories, family feelings and devotion from all those who purled, cabled and edged to achieve this world record. This money, alongside that achieved through the direct auctioning of some of the blankets, will go towards ensuring that no-one has to cope with dementia on their own: providing the information, advice and practical support to live well with the illness. Donations should be made via the dedicated JustGiving page www.justgiving.com/argyllandclydereion; alternatively, our Dementia Resource Centres and other services across Scotland will also have collection boxes where you can give your £2 blanket donation.

David Bellamy plants tree at allotment project



On 1 July we were delighted to welcome world-renowned conservationist Professor David Bellamy OBE to our allotment project in Glasgow's Bellahouston Park.

Professor Bellamy planted a yew tree (symbolising growth and renewal) while Scottish singer/songwriter Dougie MacLean OBE played his well known anthem "Caledonia". The event was the

brainchild of Davey MacRoberts, a full-time carer for his mother, who has dementia.

Gardening has been shown to be of significant psychological, social, mental and physical benefit to people with dementia, promoting friendly interaction and activity in a relaxed setting. Activities such as gardening have also been shown to help maintain a sense of identity and to boost self-esteem in people with dementia.

The yew tree was been propagated from a specimen that is at least 2000 years old, sourced by the Conservation Foundation (founded by Professor Bellamy and David Shreeve, 30 years ago) and purchased by Davey MacRoberts for the event.

For once, the weather was on our side and a lovely afternoon was enjoyed by people who take part in the allotment project, their families and others who have lent support to the project and our services.

Brain Tissue Bank goes live

The Scottish Dementia Brain Tissue Bank, supported by Alzheimer Scotland, is now live. Brain tissue banking is our main hope for curing Alzheimer's disease and other forms of dementia. This is because the changes that lead to memory loss, behavioural changes and other features of dementia all occur within the brain.

To make a real difference, scientists need to find out exactly what happens inside people's brains when they have Alzheimer's disease or similar conditions, but this can't be done while they are still alive. Donating brain tissue for research after death and linking this to how someone was while still alive is the only way of understanding the processes that lead to dementia.

Until now, there were no Scotland-wide facilities for collecting this invaluable legacy, which was a source of considerable upset for people living with dementia who felt strongly that they wanted others to benefit from their donation, even if they themselves could not benefit in life.

The Scottish Dementia Brain Tissue Bank will keep small portions of relevant brain tissue (not whole brains). There is no cost to the donor or his or her family nor will it delay funeral arrangements. The Scottish Dementia Clinical Research Network will co-ordinate consent from donors.

If you are considering brain tissue donation you can record your

interest via Alzheimer Scotland's 24 hour freephone Dementia Helpline on 0808 808 3000 or if you would like to find out more, contact Coleen Sloan at the Alzheimer Scotland Dementia Research Centre on 0131 650 4340; email Coleen.Sloan@ed.ac.uk. Please note that any tissue donated must be from people with dementia and not their relatives or carers who are currently healthy. Next of kin can give consent if the person involved no longer has capacity, even if there is no Power of Attorney or Guardianship Order in place.

Fundraising & local news

Wedding favours now available



Do you have a family wedding to celebrate this year? Did you know we now have our own little wedding favour cards which are becoming more and more popular with couples to use instead of traditional favours to give to their guests in honour of a family member with dementia? It's a lovely way for couples to still involve a loved one in their special day when they may be too unwell to attend.

If you'd like more information or to place an order please call the fundraising department on 0131 243 1453 or email fundraising@alzscot.org

Favours are priced at £1.50 each for cards and pin badge or £1 if you'd like the pin badge on its own.

Relaxation Day at the D'café



Donations given to benefit local Alzheimer Scotland services can often be used to fund something a bit special for people with dementia and their carers. During Dementia Awareness Week this

year, a relaxation day was held at the Midlothian D'café, where 36 people with dementia and carers enjoyed varied relaxation therapies such as head massage, leg and feet massage, manicure and nail treatments, pedicures and hairdressing.

The relaxation day was made possible when Mary McPhail, Worthy District Grand Matron of Eastern District Grand Chapter of Scotland attended the D'café with a fabulous donation of £1700 in December 2011 which she wished to be used for the benefit of people with dementia and carers in Midlothian.



Stamps at 2011 prices for some benefit recipients

Every residence in Scotland should by now have received a voucher leaflet from the Royal Mail offering a reduction on Christmas stamps for people receiving certain state benefits.

From 6 November until 24 December 2012, customers who are receiving Pension Credit, Employment and Support Allowance, Incapacity Benefit or Unemployability Supplement can purchase up to 36 stamps in book format at the Christmas 2011 prices. The stamps can be 1st Class in books of 6 or 12, and 2nd Class in books of 12. Customers can purchase the 36 stamps as all 1st Class, all 2nd Class, or a mixture of the two. The stamps can be purchased at all Post Offices.

First class stamps will cost 46p (usually 60p) and second

class stamps will be 36p each (usually 50p).

When you have your voucher you will need to complete it and take it to a Post Office branch along with proof that you receive the relevant benefits.

Proof can be either:

- a letter from the Department of Work and Pensions, or
- a Post Office Card Account Statement, or
- a letter from the Service Personnel and Veterans Agency

The documents must be dated within the past 12 months and must name the relevant benefits.

If you are unable to get to a Post Office yourself, then someone else can collect your stamps for you. They must present the voucher form completed and signed by you, along with your proofs of receipt of the relevant benefits.

If you have not received a voucher, have lost it or if there is more than one eligible person in your household, you can order a voucher by calling Royal Mail Customer Services on 08456 016 248, no later than 18 December.



Tanya Cox, Jenny and Linda Morrison.

Supermarket sweep

Some supermarkets run schemes whereby customers can pop a token in a box to nominate one of several charities to receive a donation. Why not keep an eye open for a scheme operating in your area and nominate Alzheimer Scotland to be one of the selected charities?

One of our supporters, Jenny Smith from Huntly, nominated us as one of three charities for customers to choose from in her local ASDA store. ASDA later asked Jenny if she would collect the cheque on our behalf.

Jenny said: "Everyone was delighted I was wearing the t-shirt - the representative from the local Nordic Ski Centre, who was also collecting a cheque, commented that his grandad had Alzheimer's and he had done a sponsored climb last year to raise funds for your charity, and they too had worn the t-shirts!

"The money came from ASDA's Huntly Community Fund and the recipients are decided as follows. Every two months they have 3 nominated charities and customers are given tokens when they spend a certain amount at the till which they then choose to put into one

of the three boxes. Generous folk also put their change in the boxes. At the end of the time the tokens are counted and the charity with the most gets £100 plus any money in the box. The remaining two charities get £25 each plus any money in their box. The winner on this occasion were the Marie Curie Nurses and we came second".

Jaguar Enthusiasts Club donates £5,000

This year, the Jaguar Enthusiasts Club Grampian Region selected Alzheimer Scotland as the charity to support via the proceeds of their Annual Gathering and Car Show at Drum Castle on 29 July.

Despite the wet weather there was an excellent turnout of cars and visitors with a record number of Jaguar cars (62) on the lawn from as far afield as Orkney and Huddersfield.

With the money raised on the day plus the pledges and donations from their corporate sponsors, the Club are donating £5,000 to our services in Aberdeen and Aberdeenshire to help with our work in the region. Many thanks to Henry Riddoch and his fellow enthusiasts for their generous donation.

Tesco Charity of the Year Partnership success continues

Although the Charity of the Year Partnership with Alzheimer's Society and Tesco came to an end in March, the good news continues. At this year's Business Charity Awards, we were awarded Best Charity Partnership (Retail and Leisure) beating off some serious competition from other leading retailers and their charity partners.

The Partnership raised over £7.5 million UK wide, Tesco's most successful charity of the year partnership so far. Scotland's share of this amazing sum is being used to fund

- our Dementia Community Roadshow, taking information to and raising awareness of dementia in our local communities
- five Dementia Advisor posts
- expansion of our Dementia Helpline to include an e-helpline service.

"Having an e-helpline as well as a traditional helpline allows people to contact us in whatever way is best for them, particularly as many people can also access their emails on the move via mobile phones."
Elaine Harley, Dementia Helpline Manager

Our new Dementia Advisors are now in post, our Roadshow has already reached in excess of 2500 people across Scotland and our e-helpline service is in its early stages of development. These achievements would not have been possible without the amazing support of Tesco staff and customers across Scotland, for which we are extremely grateful.

Alzheimer Scotland AGM 2 November

Attention all Alzheimer Scotland members

This year's Annual General Meeting and Conference will be held on Friday 2 November at the Hilton Glasgow Grosvenor Hotel. The usual notices will be issued prior to the AGM but do get the date in your diary now. This is your opportunity to meet members of our governing body and senior staff and to hear more about Alzheimer Scotland's work over the past year.



Fundraising events

Most of our 2012 outdoor events have already taken place but we still have some fun events coming up before Christmas.

Bonfire Firewalk

(over 18s only please)

**Saturday 27 October 2012 and
Sunday 4 November 2012**



We are excited to announce our Firewalk events on Saturday 27 October, Falcon Square, Inverness and Sunday 4 November, Govan Road, Glasgow— just in time for Bonfire Night. Trek 20 feet across embers that are burning up to 1200°F in support of Alzheimer Scotland.

You need absolutely no previous experience as all the training will be given by professional instructors on the night. After an in-depth training seminar you will undertake this exciting and truly thrilling challenge

event. Friends and family are welcome to come along to watch with a few fundraising games and raffles to keep them busy whilst you undertake this walk to remember.

For the Inverness event we ask participants to raise a minimum of £250 each to take part; for Glasgow, to sign up you pay a deposit of £20 and raise a minimum of £120. Once the target of £120 has been reached participants can choose to have their deposit refunded so they take part for free!

Contact Rachel Laming

Community and Events Fundraiser
on 0141 946 0966 or
rlaming@alzscot.org

Challenge Scotland Winter Events 2012

**Inverleith Park, Edinburgh
Sunday 2 December 2012**



Alzheimer Scotland is once again proud to be involved in this year's

Challenge Scotland Christmas events. There are four events to choose from: a 5k Run, a 6 mile Walk, the Golden Tinsel Mile Walks, and the Santa Toddle for the little ones. There's also a Christmas Fayre and festival on the day.

To take part in Challenge Scotland you must register online at www.challengescotland.com

If you want to use the event to fundraise for Alzheimer Scotland please let us know by emailing the Events Team at events@alzscot.org or calling the events line on 0845 260 0789. Even if you've already registered and haven't chosen a charity to support - it's not too late! We will then send you out a sponsorship pack as a thank you for running for our cause.

Ladies - a date for your 2013 diary

On Friday 1 March 2013, Alzheimer Scotland will be holding its first ever Ladies' Lunch in a central venue in Glasgow. More details will follow in a later edition of Dementia in Scotland.

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