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Alzheimer Scotland
Action on Dementia

Dementia in Scotland

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Benefit changes coming in 2013

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Delivering integrated dementia care – a new model

Chief Executive's **comment**

On behalf of everyone at Alzheimer Scotland I would like to wish all our readers and members the very best for 2013. I hope you enjoyed the festive season and I look forward to sharing our news with you as we continue to make progress in our quest to improve the lives of people with dementia, their partners, families and friends throughout 2013.

So much happened in 2012. One real achievement was that we opened up new Dementia Resource Centres in Kirkcaldy, Greenock, Inverness and Dumfries, each of them helping to bring us and our cause closer to local communities. Taking dementia 'to the High Street' in this way also helps to diminish the stigma and fear that too many people have had to live with for too long. The Centres have all been extremely well supported by local people and received significant financial contributions from various local fundraised initiatives. Without this support it would not have been possible to open so many new resources and I would like to pass on my sincere thanks to every person, business and Trust that has helped make this possible.

You will also see in this edition that we recently launched two major initiatives in partnership. We opened a new Alzheimer Scotland Policy and Practice Centre with the University of the West of Scotland; and we launched a new Football Reminiscence Hub at Hampden Stadium with our partners at the Football Museum and support from BUPA and the People's Postcode Lottery. This year we have also enjoyed new partnerships with organisations such as Glasgow School of Art, Dogs for the Disabled and RNIB, our partners in the Dementia Dog initiative. We have also witnessed the evolution of very many new partners and supporters as part of the large number of exciting new Dementia Friendly Community initiatives that are developing across the country. These new partnerships build on the long-standing relationships that we have with our local authority and NHS partners and our colleagues across the Third and Independent Sectors.

These new partnerships and the desire for people in communities and organisations to help our cause has been both overwhelming and inspiring, and I look forward to building on them this year. Dementia is becoming everyone's business; and I truly hope this makes a huge difference to the sense of belonging and security that people living with dementia enjoy in our communities.

We believe that these many creative and constructive partnerships demonstrate that Scotland is beginning to truly face dementia together. This year we must build on this. The work of our closest partners, the Scottish Dementia Working Group and the National Dementia Carers Action Network, will be vital in ensuring we fully achieve the changes we all want to see.

Together with all our partners, with our many thousands of members, our army of volunteers, our many supporters and our dedicated staff we are an immense force for change. And together we can make 2013 as historic and successful as 2012.

Henry Simmons
Chief Executive, Alzheimer Scotland

Alzheimer Scotland News

Centre for Dementia Policy and Practice launched at University of the West of Scotland

Monday 10 December saw the launch of Alzheimer Scotland's new Centre for Dementia Policy and Practice, which will operate within the University of the West of Scotland's Institute for Older Persons' Health and Wellbeing, launched on the same day.

The Centre will be led by Debbie Tolson, Alzheimer Scotland Professor of Dementia and Director of the Centre. She will work alongside the recently appointed Alzheimer Scotland Professor of Dementia Care, Dr Graham Jackson, and an Alzheimer Scotland Reader/Senior Lecturer in Dementia Care (yet to be appointed).

Professor Debbie Tolson

Chief Executive of Alzheimer Scotland, Henry Simmons, said "We are delighted to launch this new Centre in partnership with UWS. No-one should underestimate the size and scale of the problem facing us in Scotland and beyond. UWS is stepping forward and taking up this challenge and we are extremely pleased to work in partnership with them. We hope others will follow this lead so that we can fully address one of Scotland's most pressing public health issues".

The UWS Institute of Older Persons' Health and Wellbeing aims to establish a centre of excellence, advancing knowledge relating to ageing, with a view to improving the health and quality of life of older people. It brings together the skills and knowledge of staff within higher education institutions, the NHS, local authorities, businesses, and not-for-profit organisations, in order to promote the development of policy and practice relating to older people.

Alzheimer Scotland Nurse now in each NHS Board

Following our successful fundraising appeal (spearheaded by the Dowager Duchess of Hamilton) and with the support of the Scottish Government, there is now an Alzheimer Scotland Nurse Consultant/Specialist in every Scottish NHS Board.

This is a huge achievement in terms of improving standards of hospital care for people with dementia in Scotland. Our Dementia Nurses will work closely with their NHS colleagues, particularly the Dementia Champions, to implement key strategic targets for dementia care in our acute hospitals.

Many of our Nurse Consultants were able to attend the launch of our Centre for Dementia Policy and Practice. They are pictured here with Kay Hamilton and some of Scotland's Allied Health Professional (AHP) Consultants, including Elaine Hunter, National Allied Health Professionals Consultant, who is seconded to Alzheimer Scotland for two years to provide strategic and professional national leadership and advice for this key group of staff in Scotland. The next issue of Dementia in Scotland will include an article on the role of the Allied Health Professional in dementia care.

Alzheimer Scotland opens **Hampden Hub** and launches **Football Memories League**

Kenny Valentine (Bupa), Clara Govier (People's Postcode Lottery) and John Laurie (Alzheimer Scotland) officially open the new Hampden Hub

At the end of November we were delighted to officially open our brand new resource at Scotland's national football stadium, the Hampden Hub. This will also be the base for the Football Memories League – the latest development in our Football Memories Project.

Former footballers Peter Cormack, Billy Hunter, Alan Anderson, Colin Jackson and the legendary Lawrie Reilly were on hand to celebrate. None of this would have been possible without the tremendous support from players of People's Postcode Lottery, Bupa Care Homes and the generosity of countless groups and individuals across Scotland.

The Football Memories League has Divisions based on geography, with 30 teams across Scotland. The people taking part in the groups have all chosen their team name and their team colours, giving a sense of belonging and provide an identity. The Hampden Hub provides access to an image collection which is unique in football and will cater for the wide range of teams which our people support. Hub staff will co-ordinate the national project and support for the staff and volunteers who are involved.

New Dementia Resource Centre for Dumfries

Our latest Dementia Resource Centre officially opened on 18 October at an event attended by local MSP Elaine Murray, Alzheimer Scotland's Convener John Laurie and Chief Executive Henry Simmons, along with major donors towards the centre, local volunteers and staff.

The move to the new premises at 8 Gordon Street, Dumfries was the shortest move in our history, from our previous address at 1 Gordon Street but represented a huge amount of work for our staff team getting the beautiful new centre fitted out while keeping our services going. But all the hard work was worthwhile.

The new Dementia Resource Centre will be used in a variety of ways to increase the local support opportunities available to people with dementia. It will run day and evening care services, therapeutic activities, carer support and education, peer support groups, self-management courses and training for staff and health care workers. It will also provide an advice and information service. The Centre will also be used to develop new activities such as exercise groups, football reminiscence activities, singing groups, a café and baking/ cooking groups. Such activities are vital in reducing the social isolation of people affected by dementia; providing a relaxed social environment and an opportunity for people with dementia and their carers to meet others in the same situation. It will also display volunteering opportunities and be a resource for other organisations and Alzheimer Scotland services in the region.

Move for Stranraer Services

Not to be outdone, our Stranraer and Wigtown Service has also been on the move. After a few hiccups and delays, our Stranraer Resource Centre is now up and running at 67 Hanover Street. The first event to be held in the new facility was the Forget me Not Café, which was a huge success and feedback from all those who attended was very positive. We will also be running support groups and our Football Reminiscence group at the new premises.

We now have two new posts to add to our existing staff team of Lynne McGhie, Project Worker; Judi Shaw, Dementia Advisor and Caron Kennedy-Stewart, Service Administrator. Shona Sneddon takes on the role of Community Post Diagnostic Worker and Kirsty Ashbridge is now Community Activities Organiser in addition to her existing duties at Stranraer Day Care.

Motherwell Town Centre – aiming to be a Dementia-friendly community

On World Alzheimer's Day 2012, Alzheimer Scotland, NHS Lanarkshire, North Lanarkshire Council, and VOX (Voice of Experience) got together to launch Motherwell as the first dementia-friendly town centre in Scotland. Fifteen businesses agreed to sign up to action plans on the day, including Asda, Boots, Strathclyde Fire & Rescue and Funtastica Homestyle. Their commitment will lead to dementia-friendly status being achieved when their action plans are completed and evaluated.

The sorts of issues in the action plans include staff being given hints and tips guides to carry with them, staff awareness sessions and support with signage.

Those attending the launch event heard representatives from the various organisations involved but also from Agnes Houston from the Scottish Dementia Working Group who spoke passionately about her need to keep well and active and what helps and hinders that aim in her community.

The Dementia Friendly Community working group is now tasked with supporting each of the 15 businesses with their plans and developing sessions and other tools for support. It will then follow up on the remaining 280-plus businesses in the Town Centre who have already received information on how they can get involved. This is a work in progress, so watch this space!

New Branch in Inverclyde

Our new Inverclyde Branch held its first AGM in October following a busy year which involved attending conferences, raising funds through various activities, taking part in several representative groups, holding two awareness raising events and starting up a social/ activities group in Gamble Halls, Gourock (every Monday 1.30-4pm), to name but a few. The aims of the Branch are to campaign on behalf of people with a diagnosis and their carers, respond to public consultations, raise awareness of dementia, and organise activities to help those with a diagnosis and their carers.

Branch members meet on the 2nd Tuesday of every month (1.30-3pm) in "Your Voice" premises, 12 Clyde Square, Greenock. For more information, contact Rose Mary Bowes, Branch Chair, Your Voice, 12 Clyde Square, Greenock, PA15 1NB.

Research Centre news

Alzheimer Scotland's Dementia Research Centre has awarded funding to Nicholas Jenkins, Chancellor's Fellow at the School of Health in Social Science, University of Edinburgh for a study piloting the use of drama to explore experiences of early onset dementia and priorities for developing specialist support services. Part of the project will include the creation of professionally acted video-vignettes, co-directed by service users, which will serve as tools for future research and dissemination activities.

Nicholas will be working with service users and staff at our Lothian Early Onset Support Service (LEOSS). This project represents the initial stages of a long-term research and knowledge exchange relationship with staff and families at LEOSS.

First Jim Jackson Essay prizewinner

In September 2011 when we launched the Alzheimer Scotland Dementia Research Centre, based within (and in partnership with) The University of Edinburgh, we also launched the Jim Jackson Essay Prize, which commemorates the late Jim Jackson OBE, former Chief Executive of Alzheimer Scotland, who provided the vision for the founding of the research centre.

The first winner of this prize is Edinburgh University 4th year medical student, Liana Romanuik who received a very welcome cheque for £500 for her moving essay entitled "Painting on torn canvas". Jim's widow Jennie and their daughter Fiona were among those present to see Liana receive her award from Professor John Starr and Alzheimer Scotland Chief Executive, Henry Simmons.

Liana, centre, with Professor Starr and Jennie Jackson

You can read Liana's essay on the research centre website at www.alzscotdrc.ed.ac.uk/images/liana%20romaniuk%20essay.pdf

Maintaining standards across Scotland's care services: understanding the work of the Care Inspectorate

The Care Inspectorate regulates and inspects care services across Scotland. As well as ensuring that services are delivered to a high standard, the Inspectorate is playing an increasingly important role in promoting best practice. Dementia in Scotland spoke to Annette Bruton, the Care Inspectorate's Chief Executive, to discover how the organisation is responding to the changing needs of people with dementia receiving care in Scotland.

How does the Care Inspectorate's work impact on people with dementia?

We monitor standards in Scotland's 900 care homes, as well as inspecting care services in the community. Our most recent care home census showed that half of all residents in Scotland's care homes have some degree of dementia. Just over 8% of care homes said they considered dementia care to be their main area of provision. That's a hugely important group of people we're serving. As well as carrying out a yearly census, we collect information through a more detailed annual return. On the most recent return, 73% of care home services said that they were equipped to care for people with dementia. That implies the other 27% don't feel equipped. It's a significant statistic and shows there is a lot more work to be done to ensure that people with dementia receive the highest standards of care.

I see our role as not just regulatory but providing advice and support. This involves helping all services that provide care for people with dementia gain the skills to provide the highest quality care. Equally, if at any time standards fall below what we consider to be acceptable, we take immediate steps to protect anyone who is receiving care, whoever and wherever they are.

As well as being responsible for care homes, we also inspect community-based services which are widely used by people with dementia. As self-directed support becomes established we will inspect this too.

How do you ensure your inspectors have the specialist skills needed to capture the views of people with dementia?

We use a range of approaches to make sure our inspection teams can gather the views of people with dementia and understand their care needs.

We currently use Talking Mats * as a communication tool, both for people with dementia and other people who may have communication difficulties. This is a very effective way of gathering information directly from people who use services.

In addition, we are working with the Care and Social Services Inspectorate Wales to introduce the Short Observational Framework for Inspection 2 (SOFI 2). This was developed by the Bradford Dementia Group and the Care Quality Commission. It is based on Dementia Care Mapping and is designed to help inspectors capture the experiences of people who use services, but who may not be able to express their views themselves. SOFI 1 was already being used by colleagues who joined us from the Social Work Inspection Agency, so we already have some experience of using SOFI within the Care Inspectorate.

We are developing a toolkit for our inspectors that uses SOFI 2, and with the help of colleagues in Wales are currently looking at how it works in practice. It's intended to *supplement* talking to individuals, rather than being an alternative to this. Observable standards are useful, but actually hearing what service users and carers say is vital. Used in combination, Talking Mats and SOFI 2 are a powerful set of tools for unlocking what people who use services think.

We have also been training Dementia Champions within the organisation. They have time within their roles to stay up-to-date and put out bulletins about best practice to all colleagues.

As well as dementia-specific work, we publish self-assessment tools promoting best practice that will benefit all older people receiving care, including people with dementia. These have a strong emphasis on prevention and learning by example. An example is our new guide on managing falls and fractures in care homes for older people.

How have the Dementia Standards influenced the way inspections are carried out? Are you seeing an improvement in practice as a result of the standards?

The Dementia Standards have been tremendously helpful and we have been doing intensive training with our staff so they know what to look for and what represents best practice. We apply the standards during inspections and measure performance against them.

We don't yet know what impact the standards have had because there isn't a sufficient body of evidence. We estimate that we will need two years of inspection data to see how much of a difference they are making. However, from our perspective there are already clear advantages. Inspectors work in a much more fine-tuned way thanks to the existence of the standards. And because they receive more specialist training, they are able to highlight aspects of services that fall below the guidance set out in the standards.

How is the Care Inspectorate involving the wider public in the work it does?

We have a legal duty to listen to feedback from the public and I think we have come a long way in achieving this. Our goal is to bring more voices to a regulatory regime that has been set up on the public's behalf.

The board of the Care Inspectorate includes people who use services and their carers, and we also have a very active and important Involving People Group. Its members are volunteers who play a vital role in acting as a sounding board and watchdog, ensuring the work we do encompasses all the issues that are important to them. The group includes people with dementia and their carers. We see the group as a vital resource for understanding what people with dementia and their carers think we should be doing, rather than the other way round.

We recently published *Involving People, Improving Services*, our three-year plan for involving the public in the work we do. This was co-produced with the Involving People Group and our lay assessors. It was the group themselves who presented it to the board, and I think this illustrates how integrally they were involved in developing it.

Lay assessors play a vital role in the inspection process. They are current or former users of services – or their carers – who volunteer to take part in inspections. Between now and next Easter we will be running three pilot projects looking at broadening our inspection teams further.

The Care Inspectorate has a commitment to helping people remain in their communities for longer. How is it achieving this?

The current health and social care agenda places a strong emphasis on enabling people to remain within their communities where possible, with the provision of long-term care when they need it. Our contribution – strengthened by the new self-directed support legislation – is in developing a new model for inspection. This will reflect the entire health and social care agenda and will involve us working jointly with Healthcare Improvement Scotland.

Initially this joint work will focus on care at home, enabling us to develop a methodology that looks at the whole care journey, rather

than focusing on isolated episodes, such as an admission to a care home. Viewing the whole journey will enable us to understand the periods when people may only need a low level of support and appreciate how their needs change over time. It will also enhance our understanding of what precedes a care home admission, and help find out whether the care home system is flexible enough to allow short admissions. This 'whole journey' approach will shed light on the relationship between different agencies and how they work together. Families become very frustrated when agencies don't talk to each other.

How will the post-diagnostic support guarantee help improve care in the longer term?

The one-year post-diagnostic support period should be the time when someone with a diagnosis of dementia has truly integrated support put in place. As we assess the care delivered during this critical period, we will be able to discover how it improves long-term outcomes for people with dementia. For instance, we will be able to monitor whether care packages are suitably flexible.

How does inspecting care at home services work in practice?

This is a challenge, but the information we can gain from these kinds of inspections is very valuable. The starting point is to select enough people who are receiving care at home to provide results that give a meaningful overview of the services. We begin by reading case notes and tracking the supporting evidence. Then we visit people and see if what's written in the case history reflects what's happening in practice. We are taking a developmental approach to how these services are inspected because this is a new area. Health boards, local authorities and the private sector are supportive and there is an understanding that we will refine the process as we go along. Instead of inspecting 'the service', we are inspecting 'the outcome for people who use the service'.

How about self-directed support?

The self-directed support legislation hasn't been enacted yet so this isn't an area we are inspecting yet. Everyone is behind self-directed support, although we are aware it won't be an easy area to inspect – for example we don't have the right to go into people's homes. Our goal is to try and set up local forums that will bring people using self-directed support together. This ties in with our wider work on involving the public as much as possible. Tapping into good local knowledge will be key to the success of inspecting self-directed support services. We will also receive information through the complaints system. In terms of how they are delivered, care at home and self-directed support have a lot in common and it's likely the inspection tools used for both will converge. It may not be a straightforward and easy task, but it's hugely important and exciting.

Our role will be to capture the best processes for describing the impact of these new services so that we can describe their outcomes. This will help build an evidence-base for how effective they are. It's complex and certainly not frivolous, but I think it's a great prize if we can describe the factors that have a positive impact on people's lives.

How is the Care Inspectorate raising awareness of best practice?

The information we are capturing is beginning to track the experiences of people throughout their entire journey through the care system. At the early stages we are now evaluating community-based care. Over time we will continue to see personal journeys progress with more intensive and longer-term care often provided latterly.

We would like to develop this information so that as well as measuring quality, the public can use it to understand how care services can be of maximum benefit to them. Historically our reports have not been written from the public's perspective and we are working on reshaping these so that they tell a story about the quality and impact of care that is useful and relevant to the public. This of course will supplement our core work of ensuring that services are safe and delivered to the highest standards.

Can you describe the Care Inspectorate's role in promoting best practice?

Next year we are planning on introducing best practice conferences targeted at practitioners, as well as people using care services and their families. The idea is to bring people together to showcase examples of good practice. We felt it was important for us to provide the public and professionals with feedback following the introduction of the Dementia Standards. By the time the conference takes place the standards will have been in effect for around 18 months, so their impact should be becoming clearer. We also plan to run events on listening to people and shaping services based on the needs of users. In addition, from next year we will start showcasing the good practice that we encounter by adding it to our website at **www.scswis.com**

* For more on Talking Mats, visit **www.talkingmats.com**

Lanarkshire nurses leading by example

Front Row (L to R): Lynn Hogg, Alan Somerville, Donna Marie McRoarty, Norah McCluckie
Back Row (L to R): Maureen Taggart, Joan James, Dominique Docharty, Susan Wilson, Veronica McGuigan.

Improvements to the care delivered to people with dementia and their families in acute hospitals is, as readers will know, a key aim of Scotland's national dementia strategy. However, the media often pick up on the negative aspects of patient care and a lot of the improvements and good ideas being introduced by the people actually delivering care fail to be recognised.

I travelled to Monklands Hospital in Airdrie, at the invitation of Joan James, Divisional Nurse Director for acute services within NHS Lanarkshire, to meet with a group of Band 6 nurses (Charge Nurses and Deputy Charge Nurses) who have been coming up with their own ideas for improving the experience of people with dementia and their families in hospitals.

Before hearing from the nurses themselves, Joan gave a bit of background leading up to some of the changes that have been made in acute hospitals in Lanarkshire. Surprising to me (until it was explained) was that a catalyst for these developments was the introduction of a change of colour for nurse uniforms. The nurses felt this had an effect on how they were perceived by others – they were often the ones leading on care delivery on a daily basis but very little was being invested in them especially in relation to training, and now their familiar uniform was being changed to boot!.

Joan and her senior nurse colleagues picked up the training challenge, which has led to more than 60 charge nurses receiving training in delirium and dementia – delivered by the Practice Development Centre in NHS Lanarkshire and supported by the Alzheimer Scotland Dementia Nurse Consultant, Maureen Taggart. This was followed by five days' training at the University of the West of Scotland on their Older People's Programme – all of them graduated. The interest and enthusiasm engendered by this training meant that the nurses wanted to take the lead on developing new initiatives in their own wards and departments. This enthusiasm was replicated across the three main acute hospital sites in Airdrie (Monklands), East Kilbride (Hairmyres) and Wishaw, as well as associated hospitals.

All Band 6 staff now have monthly OPAC (Older People in Acute Care) meetings where they discuss good practice, sharing what works and what doesn't, and supporting each other in older people's care in whichever department they work in - acute medicine, orthopaedics, accident and emergency or outpatients, for example.

Assessing patients for possible cognitive impairment

Lynn Hogg is a Charge Nurse in the pre-admission assessment department at Monklands Hospital working with patients coming in for elective (planned) surgery. She was particularly interested in looking at the Abbreviated Mental Test (AMT) which uses four simple questions to flag up potential cognitive impairment and the need for further assessment:

- How old are you?
- What is your date of birth?
- What is this place?
- What year is it?

A score of 3 or less would lead to a referral for further investigation. Lynn has a standard letter which she sends to the person's GP or consultant saying what the AMT score was. This may be the first time that the GP becomes aware of a possible problem.

(An AMT should be carried out with any older person coming in to hospital but it is not always done, as some inspections of acute hospitals have shown).

Lynn realised that the best way to implement changes or procedures is through staff understanding not only what to do but why they are doing it – this makes them more aware and more focussed. Having implemented a staff awareness package, Lynn has audited on a weekly basis whether or not staff are carrying out the AMT as

required. They are, with 100% compliance recorded in the few weeks leading up to my visit.

Lynn also gives out a form called *Getting to know me* to individuals or carers for them to complete giving information about the person's life, likes and dislikes, key relationships, etc, so this information can be incorporated into the person's care while in hospital.

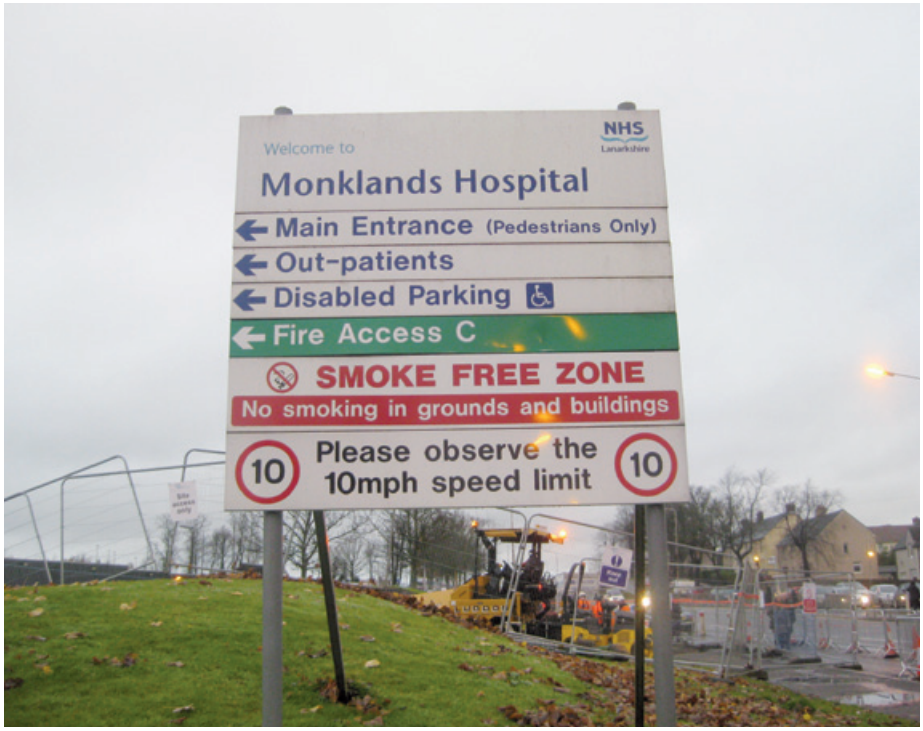
Intentional rounding

Alan Somerville works in the Renal Unit, both in the ward and in the dialysis unit. Like Lynn and the other nurses I spoke to, he also uses the *Getting to know me* form to help deliver good personalised care. Surprisingly, he also applies AMT screening in his work. As he says, some chronic dialysis patients often don't go to their GP as they are seen so regularly in hospital – the AMT screen in the renal unit may be the first sign of a possible cognitive impairment which needs to be flagged up to the GP.

Alan spoke about the introduction of intentional rounding in his ward. This is not some arithmetic calculation, but the practice of taking time to specifically ask patients on a regular basis if they need to go to the toilet or if they need anything else, rather than waiting for the patient to call for assistance. This sounds like an obvious thing to do, but anyone who has visited a relative in hospital knows that sometimes the call for assistance comes too late and there is an "accident" – unpleasant for everyone and certainly not dignified for the patient.

"Getting to know me" in practice

Donna Marie McRoarty is Charge Nurse in Ward 2 - Infectious Diseases, and a Dementia Champion. She gave some very good examples of how the information in *Getting to know me* had been used to develop good relationships with patients' families as well as helping to understand patients better. In one example, a younger person with dementia needed to have a CT scan but was very agitated and staff were considering sedation. His form suggested that he would settle well if given a cup of coffee, so that was what staff did and the patient was then happy to get the scan.



Testing change

Donna Marie also showed me examples of the range of work sheets for testing change that she has introduced in her ward, as well as a sample treatment plan form she is piloting for testing and treating patients for infections, under the Adults with Incapacity (Scotland) Act. The pilot grew out of a realisation that there was poor compliance with AMT screening and consideration of the Adults with Incapacity Act as a routine part of hospital admission and development of treatment plans.

Each work sheet gives a description of the situation, the background, an assessment of what needs to be done and a set of recommendations. It then follows a cyclical Plan, Do, Study and Act format. A Plan is drawn up listing the tasks needed to set up each test of change together with the name or names of those responsible for carrying out the task, when and where it is to be done. The Do section describes what actually happened when the test for change was conducted. The Study section describes the results and how they may be improved; while the Act section describes what modifications need to be made to the plan for the next cycle of change.

Outpatient clinic record sheet

Norah McCluckie is Deputy Charge Nurse in the Orthopaedic Outpatient Department where they can often see 70 patients per clinic with sometimes 2-4 clinics all going on at the same time. Although they try hard to fast track people over 60, some days it is easier than others. Norah had observed that patients coming in alone or even those with a relative often couldn't remember what had happened or been said at the clinic. So she devised a very simple form which is given to the patient and records the date attended, who the nurse and doctor were, what the doctor said and whether or not the person has to return to the clinic and when. It also gives a contact number for the clinic and for ambulance transport.

This simple but effective form is now being rolled out to other departments; patients and their families are happy to have a written record and Norah has noticed a drop in follow up calls from family members and care home staff who now have a better idea of what happened at the outpatient clinic.

Changes in Accident & Emergency

Veronica McGuigan works in A&E where they see over 200 patients on a normal day, about a quarter of them aged over 65. A&E can be a very noisy, frightening place, particularly for someone with dementia, so Veronica and colleagues have been working hard to change that. A room in a quieter part of A&E has been identified giving a more relaxed friendly environment where family members can be with their relative. Staff triage those over 65 to get them seen quicker and each patient undergoes an AMT screen as well as being assessed for risk of falls. Signage has been improved and commodes with contrasting coloured seats purchased. Relatives are asked to fill in the *Getting to know me* form in A&E too. Veronica explained that it's important to get things right from the start – the patient's experience in A&E can affect the rest of their stay in hospital and it's also important to get the paperwork right – if not, it can cause problems for staff in the wards.

Food is now being delivered to A&E – often people get hungry waiting. Giving someone a sandwich and something to drink can help bring down anxiety levels.

Dementia Champions – spreading the word

Dominique Docharty works at Hairmyres Hospital where she is also a Dementia Champion. She said she had been inspired by her colleagues at Monklands to put similar changes in place, including the use of a red triangle to indicate a patient whose cognitive ability was of concern. She had introduced orientation boards in each ward which display visiting times, meal times and what happens during the day, which patients and relatives seem to appreciate. She has also trialled clutter boxes where patients can put their odds and ends out of the way during meal times so their trays aren't cluttered and they can concentrate on eating. Speaking about her role as a Dementia Champion, Dominique says she is now being asked to help staff on other wards who are caring for people with dementia. The local psychogeriatrician had also experienced fewer referrals from other parts of the hospital – staff seem to be problem solving for themselves and are becoming more knowledgeable, using Dementia Champions for advice as required.

Green boxes

Several of the nurses and the sample paperwork they showed me mentioned green boxes. This is a system to highlight and identify where capacity assessments are required. Green boxes are drawn on the patient whiteboard and act as a prompt for staff to ensure patients' capacity for consent to treatment is considered. They also act as a communication aid between nursing and medical staff. Susan Wilson, Charge Nurse in Orthopaedic Trauma and a Dementia Champion explained more.

Nursing staff draw a green box on the whiteboard next to a patient's name when they believe a capacity assessment is required. A blank green box indicates that an assessment has not been completed. If medical staff have carried out a capacity assessment and determined that the patient has capacity to make decisions about some or all aspects of his or her treatment a line is scored through the box. Where an assessment establishes that the patient does not have capacity to make decisions about their treatment, the green box is completely coloured in, indicating that that the required certificate of consent to treatment and associated treatment plan has been put in place.

Within two months of introducing this new system, Susan says there was 100% compliance. There have been some dips but to no lower than 90% - and there has been a reduction in psychogeriatric referrals at the same time.

Dementia friendly environments

Joan and her colleagues are making a huge effort to create a better experience for people with dementia and their families. Staff are working in partnership with the Estates Department to produce and implement a specification for dementia friendly wards and departments; better signage and clocks have been introduced to help orientate patients; coloured crockery has been introduced; carer coordinators have been introduced at each of the three main hospitals and carers champions are being recruited for each ward.

Hospital inspections

Each of the 3 acute hospitals in Lanarkshire have undergone inspections by Healthcare Improvement Scotland – announced and unannounced. I asked Joan James if that was daunting experience?

While Joan agreed that inspections can be pretty scary at the time, they can be a force for good – identifying the strengths in services and giving credit where it is due. Where weaknesses are identified they can act as an incentive to improve further and a justification for more resources or funding for additional staff training, for example.

Maureen Thom
Editor, Dementia in Scotland

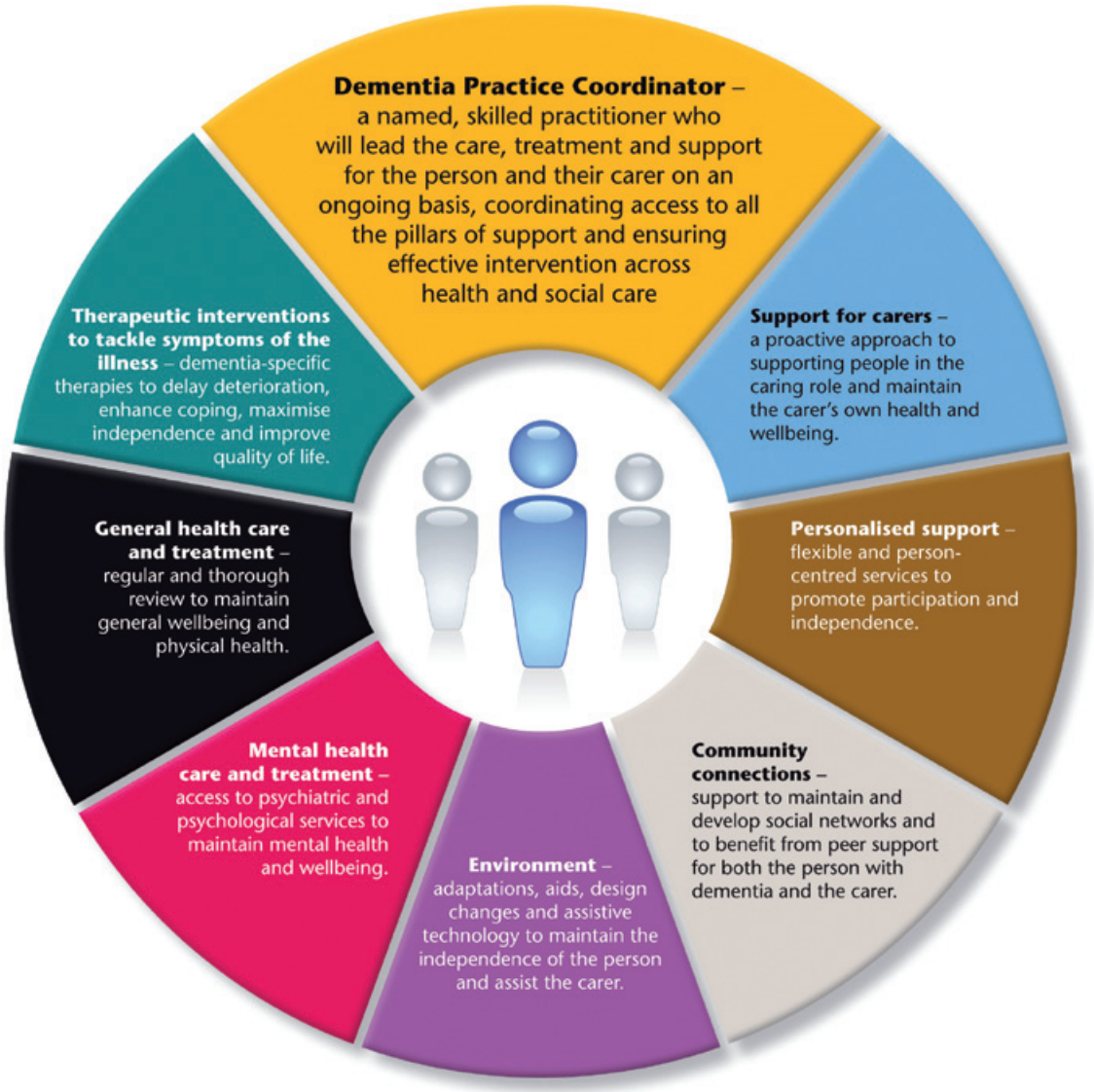
Delivering Integrated Dementia Care: new model of community support from Alzheimer Scotland

Scotland has made significant progress in addressing the key priority areas set out in the Dementia Strategy in 2010, and in the Scottish Government's commitment to a guaranteed one year's post-diagnostic support from a named and trained person, based on Alzheimer Scotland's 5 Pillars model. However, the present lack of cohesion between health and social care services means that there is still much to be done to ensure that all people affected by dementia have access to consistent, therapeutic, high quality, personalised support services.

Alzheimer Scotland has developed a new integrated model of care for people with moderate to severe dementia living in the community, which is described below. The Scottish Government's plans to integrate health and social care provide an ideal opportunity for changing how services and support are delivered to people with dementia, their partners and families.

Alzheimer Scotland's new report, *Delivering Integrated Dementia Care: the 8 Pillars Model of Community Support*, calls for a radical reform of the way we deliver community care services for people with dementia, their carers, partners and families. This is the first major public health report to demonstrate the real difference that could be made to people's lives through the integration of health and social care in Scotland.

The report presents a blueprint for the future: a model that will enable health care interventions to work hand-in-hand with social care interventions. It shows that dementia is an illness with many



social implications, one which can be tackled most effectively through a model that **integrates and co-ordinates health and social care** to best meet the needs of the person with dementia and the people supporting them.

This new model builds on key developments in relation to post-diagnostic support by providing a vision of how the care of people with dementia living at home with moderate to severe dementia can be similarly transformed.

Aim of the 8 Pillars Model

The key aim is to build the resilience of people with dementia and their partners, families and carers to enable them to live in the community for as long as possible. It also aims to build on the one year post-diagnostic support guarantee to ensure the impact of the investment in early intervention is not lost.

Each factor of the illness influences every other factor, and impacts on the overall health and wellbeing of the person and his or her carer.

When people with dementia do not receive appropriate care and treatment for the symptoms of their illness, they become more disabled than they should more quickly. Without the right support, there is a gap between how people actually function and how they could potentially function. It is important to see the potential to improve the lives of people with moderate to severe dementia living at home.

The 8 Pillars Model combines the health and social care interventions required to respond to each aspect of the illness and provide support to the carer. It promotes independence, citizenship and the right to participate as fully as possible in society.

Who is the Model for?

The one year's post-diagnostic guarantee will provide those newly diagnosed with early stage dementia with support with adjusting and managing the likely impact of the illness, both emotionally and practically. The 8 Pillars Model will then provide a coordinated approach when people need more support to live in the community.

There will, of course, be some people who are diagnosed at a later stage or whose dementia progresses more rapidly who may not be able to benefit from the post-diagnostic support model; for them, the 8 Pillars Model will be needed immediately after diagnosis.

A bio-psychosocial model

Dementia is the interrelationship of neurological damage and psychosocial factors ; the experience of the illness is subjective and unique to each individual. A bio-psychosocial model of dementia brings together what is true in the medical and social models of the illness. It provides a framework for understanding the range of factors that determine the nature of dementia, progression of the illness and appropriate interventions.

Effectively tackling the symptoms and consequences of dementia requires a coordinated range of health and social care interventions. The main intervention for dementia is human care and treatment; this encompasses a range of therapeutic, psychosocial and psychological treatments.

Supporting the carer

The experience of caring is also unique to each individual; it is influenced by a range of objective factors (relating to the tasks or activities of caring) and subjective factors (representing how the carer feels about their role).

Interventions to support the carer must meet their specific needs and circumstances in order to be effective.

Keeping the status quo?

Demographic changes and financial challenges mean that current models of care are not sustainable in the longer term. The integration of health and social care provides an opportunity to create a structured, coordinated and strategic approach to community support for people with dementia and their carers.

The 8 Pillars Model provides local authorities and NHS boards with a blueprint for restructuring integrated dementia care so that resources are used to greatest effect.

For further information on the report and the 8 Pillars model contact:

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New benefit changes could affect people with dementia

In 2013, some major changes to benefits will be introduced across the UK. If you have dementia and are aged 64 or under, or if you care for a person with dementia and receive benefits, you may be affected.

What are the main changes?

The two main changes will be the introduction of **universal credit** and the replacement of disability living allowance with a new **personal independence payment (PIP).**

Universal Credit is a single benefit that will replace lots of other separate benefits. These include:

- income support
- income-based job seekers allowance
- income-related employment and support allowance
- housing benefit
- child tax credit
- working tax credit.

Disability Living Allowance (DLA) will be phased out and replaced with the Personal Independence Payment. The aim is to cut the DLA bill by 20%, and one of the lower rates of DLA will be abolished altogether. As a result of these cuts, some people will receive less money and fewer people will qualify under the new rules for PIP.

What is the background to the changes?

The changes are being introduced by the Westminster government to try and make the benefits system less complex, and to encourage more benefit claimants into work. The current financial climate also means the government is looking for ways to reduce costs. The reforms represent the biggest overhaul of the welfare state since it was introduced in 1948.

In future, payment of benefits will be based on a stronger contract between individual and state. There is likely to be more emphasis on the individual to demonstrate their entitlement to a benefit, and benefits will come with more conditions attached.

Who will be affected?

People aged between 16 and 64 will be most affected. Although only a minority of people with dementia fall into this age group (around 3,000 in Scotland) the impact on them could be significant. For example, a person currently receiving DLA will be invited to make a claim for the new Personal Independence Payment. Also, a person who is diagnosed during the earlier stages of the illness may find it more difficult to demonstrate that they qualify for disability-related benefits.

People aged 65 and under often still have a mortgage and may still have dependent children living at home. As a result, any financial loss can have a significant impact on them and their family.

Many people who care for a person with dementia are under 65 and may have given up work or reduced their working hours to provide care. If they receive benefits, they may be affected by the changes. This could have a significant impact on the support networks around people with dementia, whatever their age.

What will the impact be?

One of the biggest changes of the benefits shake-up will be the way people are assessed. Currently, claiming benefits such as DLA involves completing a self-assessment form. Although this is

long and complicated, the person filling it in can take their time and get specialist help and advice. The new Personal Independence Payment will involve a face-to-face assessment carried out by a private company called Atos.

In 2008, when the Employment Support Allowance was introduced, new claimants had to have a face-to-face work capability assessment. We know from this process that some people with dementia didn't have their needs or circumstances accurately assessed during their interviews. Assessors require specialist knowledge of dementia in order to understand the capabilities of a person with dementia. It is not certain that all assessors have this specialist knowledge.

A face-to-face assessment can be difficult for a person with dementia, particularly if the assessor doesn't understand their needs. Some people may lose out because they will struggle with the new assessment. The Department for Work and Pensions has said that a relative or carer can be present during the assessment. This is likely to be very helpful for a person with dementia, particularly if they wish to challenge its outcome. Under exceptional circumstances, it may be possible for the assessment to take place at the person's home.

For those who are assessed correctly, many aspects of the new benefits will be managed online, such as reporting changes of circumstances. Although there is a lack of detail at this stage, an online system may also be challenging for people with dementia. The Scottish government has just published research which shows that not all people who will be claiming Universal Credit have access to the internet. Even those who could go online (at their local library, for example) may feel unable to do so because of a lack of skills or confidence. Ministers are looking at ways to help mitigate the impact of welfare reforms in Scotland, including dedicating funds to prepare claimants and support them in using this new way of claiming benefits.

Because the benefits changes are so wide-ranging and many of the details have not yet been announced, it is difficult to provide a summary of their impact at the moment. We will publish additional articles looking at the impact of the changes in detail as more information becomes available.

Coping with the changes and making sure you get the right benefits

The benefits system has always been complex, and it is a good idea to seek advice about what you are entitled to claim and how to go about claiming. If you need advice, you can talk to a welfare rights advisor. Arrangements vary in different parts of the country, but you can normally speak to an advisor who is employed by your local authority, or by contacting an organisation such as the Citizens Advice Bureau. They can provide help with existing benefits or advise you if you are making a claim for the first time.

Although the new benefits will involve a face-to-face assessment, the outcome of this can be challenged, and everyone has the right to ask for the findings to be looked at again. You can also ask to appeal the assessment. Where things go wrong, a welfare rights advisor will be able to help you through the process of challenging those decisions.

Are there any differences in Scotland?

The Scottish Parliament has no influence over most of the welfare changes. However, some aspects of the changes have been devolved to Scotland, such as council tax benefit and parts of the social fund.

In August 2012, the Scottish Government introduced new legislation which will lessen the impact of some of the welfare reforms in Scotland. In particular, this will safeguard entitlements to things like "passport benefits". These are benefits that are received automatically by people who already qualify for another benefit. For example, if you already receive higher rate DLA because of mobility issues, you are entitled to a blue badge as a 'passport' benefit. This right will continue in Scotland.

Will the changes have any benefits for people with dementia?

Some aspects of the changes may be beneficial for people with dementia. For example, the element of the Personal Independence Payment that relates to daily needs (formerly personal care) now makes provision for people who have difficulties dealing with money or planning their finances. This is an area that is potentially very helpful for some people with dementia.

Also, it is currently very difficult for a person with dementia to get higher rate mobility benefit, but the new assessment will take both mobility and the person's ability to plan and follow a journey into account. Although it is not clear how much weight will be given to the journey planning element, this could be helpful for a person with dementia.

Where can I get further advice and information?

If you are concerned about the proposed changes, you can phone our free 24 hour Dementia Helpline (0808 808 3000) or contact a local advice agency such as the Citizens Advice Bureau (www.cas.org.uk). Your local authority may provide a welfare rights service and contact details should be available on their website.

Forget-me-not project goes from strength to strength

In partnership with

Person First... dementia second

Alzheimer Scotland's Forget-me-not project, based in Glasgow, is now four years old. The project has recruited and trained over 320 volunteers who offer emotional support to people with dementia who are living in care homes or hospitals. Volunteers might visit a particular individual regularly or take part in group events.

Staff at Bupa's Quayside Care Home having raised funds by holding a Memory Walk

The volunteers get involved for different reasons. Some have family or friends who have dementia; others want to volunteer to develop new skills.

"My friend's Gran was recently diagnosed with dementia…. I have been trying to support her. This brought back memories of my own Gran who had dementia later in life….more recently I have become aware of people affected by dementia earlier in life and I want to do something to help people and their supporters."
Forget-me-not volunteer

People with dementia benefit in different ways from the service. It's a chance for some to get out more and continue taking part in activities; others look forward to a good blether.

"I feel that I become a person again, we go on walks together, we talk about the trees and she describes them to me. She is exceptionally nice and very patient."
Person with dementia

Our Forget-me-not volunteers have supported people with dementia to carry on doing the things they enjoy. These include activities such as trips to the golf club to re-establish old friendships; visits to Frasers for a make over; a night at the opera; singing together; reading poetry; talking about past experiences in foreign lands; shared interest in music and films as well as past places and people of great importance. Family members have also welcomed the project.

"Having one to one time for my Mum from the volunteer was appreciated by her and by the home. At the time the support started my Mum was very demanding of staff time … she was also jealous and suspicious when staff gave time to other residents … having the volunteer provided respite for the staff and gave Mum the one to one time and attention she very much craved. This service was a Godsend."
Family member

Care homes are recognising the benefits too. Staff from a small care home in Glasgow, Bellisle House, and from Bupa Care Homes contributed to the early development of the project and in some care homes, Forget-me-not volunteers are involved in reviewing care plans for residents. Bupa Care Homes have also generously donated to the project's running costs.

Darren Kelly, Manager of Bupa's Quayside Care Home, explains how the service has benefited residents:

"The volunteer's dedication has been very impressive. Her kindness, compassion and ability to listen to the lady she visits has undoubtedly had a positive impact on her frame of mind. The fact that she has a friend who visits and chats with her - and probably more importantly - listens to her, is something she clearly cherishes during the visit and impacts upon her outlook way beyond her memory of the visits. The Forget-me-not project is an invaluable resource for our resident and one which has a hugely positive impact on her mental and emotional well-being."

Alzheimer Scotland depends on volunteers to carry out our vital work. Forget-me-not volunteers have also given time to other services including day care in Glasgow and East Dunbartonshire; the Scottish Dementia Working Group; our supported living accommodation service at Croftspar Place; our walking groups and Football Memories groups; and Glasgow Younger Persons' service as well as assisting with Forget-me-not Project administration.

"I'm learning a lot about being a volunteer and caring for people with dementia. When I first met with Sally [all names have been changed], her vision was very much intact; this has deteriorated within weeks and she is now practically blind. Learning how to adapt, how to change your methods of communicating, and how to really tune in with the person is proving to be a very interesting journey for me. I think that my journey as a volunteer and caring for people with dementia is helping me understand the real transition that can take place. The women I met originally no longer look the same, respond the same, feel the same...every single time I visit Sally or Mary , I have to be creative with how I care for them, how I communicate with them, how I help them enjoy the moments we spent together."
Heather, one of our Forget-me-not volunteers

The Forget-me-not project shows how much can be achieved by committed and caring volunteers. If you are based in the Glasgow area and are interested in volunteering for the Forget-me-not project visit www.alzscot.org or call Fay McCormick on 0141 418 3930 to learn more.

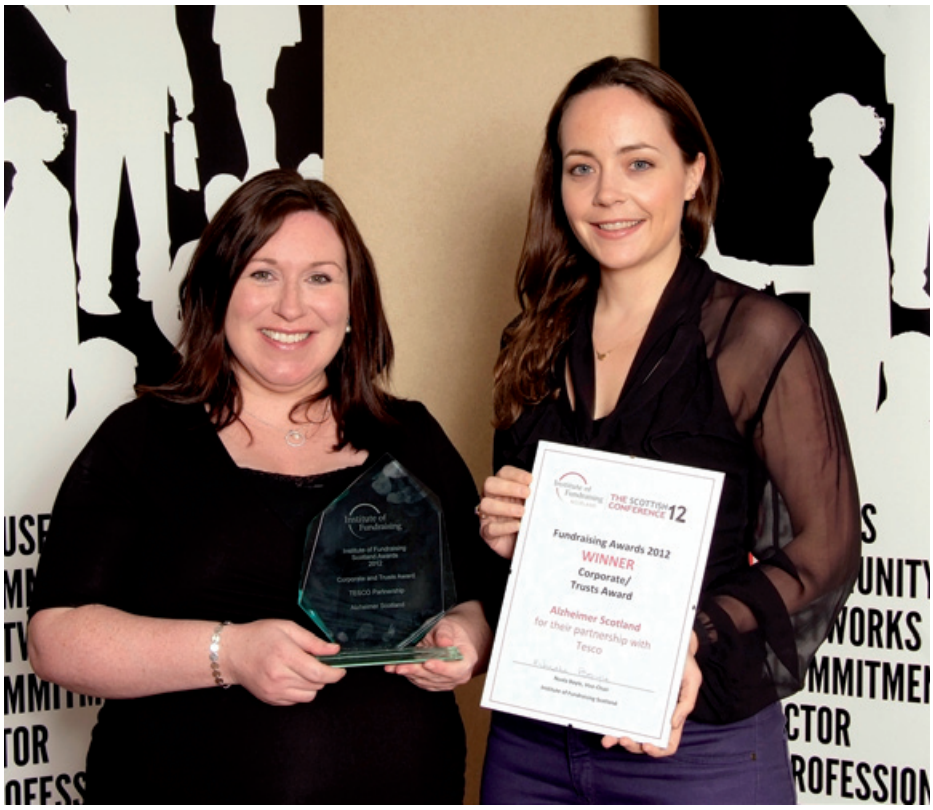
Fundraising News

Scottish Fundraising Awards success

Alzheimer Scotland was delighted to receive a trophy at the Scottish Fundraising Awards, beating off stiff competition from Cancer Research and NSPCC.

The award, in the Corporate and Trusts category, recognised the success of our recent partnership with Tesco and Alzheimer's Society, and was accepted by Corporate Fundraiser Gillian Messelink and Gloria Coats from Tesco.

The partnership with Tesco raised £7.5million across the UK. The money raised is enabling Alzheimer Scotland to fund the Dementia Community Roadshow, new Dementia Advisor posts, our e-Helpline and dementia research.



Football Memories Project chosen as Weatherseal SPL charity partner

We were absolutely delighted to win the Weatherseal SPL Charity Weekend award for 2012. Celtic legend Danny McGrain helped announce that Football Memories had won, thanks to so many of our volunteers and Alzheimer Scotland supporters and football fans voting for us, so our gratitude to all of you!

The partnership meant we would benefit from a bucket collection at the six Scottish Premier League matches on December 8th and 9th. Despite the cold and dreich weather, Weatherseal staff and helpers and some of our own volunteers were out in force at Inverness, Kilmarnock, St.Mirren, Motherwell and Tynecastle with the buckets on Saturday. On Sunday it was the Dundee derby and there was a great turn out. Sky TV filmed a session in the Board Room at Dens Park with Football Memories supporters, staff and team members, and it was shown in the lead up to the game on Sunday on Sky Sports News. The final amount raised will be officially announced after Christmas.

Coast to Coast challenge success for Andrew

Andrew Forrest, who once lived and attended school in Helensburgh, has just raised more than £5000 for Alzheimer Scotland, the biggest donation from any individual received by the Helensburgh Branch since it was formed in 2008.

He did it by successfully competing in the gruelling coast-to-coast challenge, a race that involves running, cycling and kayaking from Nairn in the east to Balluchulish in the West – a distance of 105 miles.

The man for whom he took up the challenge, Ian King, a local businessman, watched proudly as Andrew presented the money to Findlay McQuarrie, Branch Chairman, in the Dementia Resource Centre, 16 East Clyde Street, Helensburgh.

Andrew said afterwards: "Completing the 105 mile Coast to Coast was both gruelling and rewarding. In total it took 18 hours and 28 minutes and with the tremendous generosity of friends, family and supporters, the final total raised was in excess of £5000. This money will go to help fund local services in the Helensburgh area and help raise awareness of this illness. Alzheimer Scotland needs the support of local people as befrienders and helpers to add to the excellent services already provided to those diagnosed with the illness."

Mr King and his wife, Grace, expressed their pride in their son-in-law's achievement as well as their appreciation of the support given by friends and supporters in the Helensburgh community. Donations in recognition of Andrew's success can still be left at the Dementia Resource Centre.

Findlay McQuarrie
Helensburgh & District Branch

Diary Dates continued from back page

Conference – Dementia research in the UK: nations & generations

The Scottish Dementia Clinical Research Network is holding its annual 2-day conference on 21 & 22 March at Stirling Management Centre.

Day 1 Research updates from across the UK
The first day is for health professionals and researchers. Confirmed speakers include Prof. John O'Brien (Cambridge), Prof. Peter Passmore (Belfast), Dr Patrick Kehoe (Bristol) and Prof. Robert Woods (Bangor).

Day 2 How dementia affects the whole family
The second day is for the public, especially people with dementia and their carers. Speakers include Prof. Pauline Banks (University of the West of Scotland), Dr Gary Stevenson (Stratheden Hospital), Dr Maggie Robertson (Perth College) and Tommy 'on tour' Whitelaw.

Booking is now online at **http://www.sdcrn.org.uk/resources/conference-2013** or phone **01738 562 322.**

Dates for your **diary**

Dementia Awareness Week 3-9 June 2013

The 2013 Dementia Awareness Week will have the theme of 'Community Connections'. Our national conference will take place on Monday 3 June at a location still to be confirmed and will focus specifically on health and social care integration. The week will give us an opportunity to showcase best practice in local communities, ways of overcoming isolation, dementia-friendly communities, community fundraising, awareness raising and a whole host of other activities.

Fundraising events

Why not start 2013 with training for one of our running, cycling or walking events? Contact our Events Team on 0845 260 0789 or email events@alzscot.org . New events are added or confirmed throughout the year – see the Fundraising section of our website at www.alzscot.org for the latest information…

Our services in Ayrshire are benefiting from a generous cheque for £1,000 from Marcello Baldassarra – a local businessman who ran the Glasgow half marathon in memory of his father. He was sponsored by many of his customers at his chip shop in Auchinleck.

Saturday 23 March	**Zipslide across the Clyde**
Sunday, 14 April	**Rock 'n Roll Edinburgh Half Marathon**
Saturday 25 May & Sunday 26 May	**Edinburgh Marathon Festival of Running 5k & 10k on 25 May**
	Marathon, Relay Marathon and Half-marathon on 26 May
Saturday 22 June	**Martin Currie Rob Roy Challenge www.robroychallenge.com**

If you prefer a more leisurely way of raising funds for our work, there is something for you too.

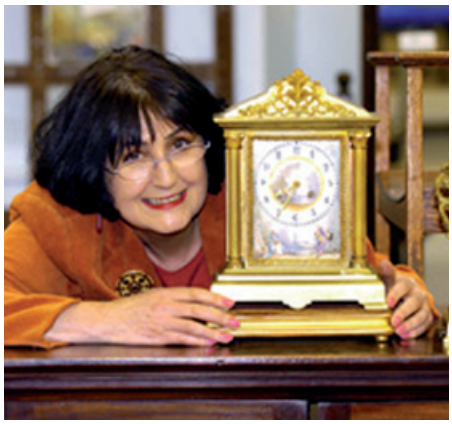
Ladies' Lunch 1 March, Glasgow

Our first ever Ladies' Lunch will take place at the Grand Central Hotel, Glasgow. Why not gather the girls together for an afternoon of bubbly, a delicious 2 course lunch, entertainment, auction and lots of chances to treat yourself to something new with stalls including handbags, jewellery and scarves.

Tickets are priced at £50 per person or £480 for a table of 10 and are available now. However we have a special Early Bird Offer of £45 per person or £430 for a table of 10 if you book before 25th January 2013, so don't delay, book your tickets today by calling our Events Team on 0845 260 0789; email events@alzscot.org

Antiques Valuation Day 25 April 2013 Chatelherault, Hamilton (10am – 2pm)

Do you have any hidden gems lying around the house? Always wanted to know if your great granny's vase is Meissen or Ming? Bring along your treasures and the experts will reveal their secrets.



Anita Manning (expert from TV's Flog It, Bargain Hunt and Antiques Roadtrip) and her team from Great Western Auctions Ltd are working alongside Alzheimer Scotland to help raise money for our new Lanarkshire Dementia Resource Centre.

A £10 entry fee includes evaluation for three items and the opportunity to meet Anita Manning and her team on the day.

Purchase tickets in advance (call our Events Team on **0845 260 0789**; email **events@alzscot.org**) or on the day.

More Diary Dates on page 19...

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Alzheimer Scotland
Action on Dementia