



# Dementia in Scotland



## Inside – We stitched the pitch at Hampden



Exclusive -  
Interview  
with Cabinet  
Secretary  
Alex Neil MSP



Dementia Dogs  
start work



Welfare reforms  
update

# Chief Executive's comment

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The launch of the second National Dementia Strategy for Scotland, which will run until 2016, is very welcome. Like the first strategy, this is a practical plan, not a high level document which will sit on the shelf. And like the first one, it has the potential to result in really significant changes for the better for people with dementia and their partners, families and carers in Scotland.

Already things are better than they were three years ago. The first strategy led to a health service target which means that in future people with dementia will be properly supported in the first year after their diagnosis. It also laid strong foundations for a better future through the Promoting Excellence framework for knowledge and skills, the National Dementia Standards, the Alzheimer Scotland Nurse Consultants, the Dementia Champions, and more.

But we're definitely not yet where we need to be. The Scottish Government has made 17 clear commitments in the new strategy. Each of these addresses an area that we know must be improved, if people are to be able to rely on being properly supported to live as well as possible with dementia. It is particularly encouraging that among these new commitments is testing out a better way of supporting people with dementia who need services in the community. This will be based on Alzheimer Scotland's '8 Pillars' model, with a Dementia Practice Co-ordinator role at the centre. It will be tested in different areas, and we believe it could radically improve the way the full range of health and social care services work together in an integrated way for each individual.

Other, equally welcome, commitments include continuing the work on better diagnosis and on post-diagnostic support, continuing the roll out of Promoting Excellence to improve staff skills and knowledge in every setting, and support for research.

One area of work to highlight is the further focus on doing better by people with dementia who may need to use a hospital. Although progress was made in improving acute hospital care under the first strategy, this is a key area where much more remains to be done. The Strategy commitment to implementing a 10-Point National Action Plan to support implementation of the Standards of Care for Dementia is therefore of huge importance.

I urge you to find out more by taking a look at the Strategy yourself.

Alzheimer Scotland will continue to be a partner and a critical friend to the Government in taking forward the new strategy. And, thanks to the involvement and generosity of our members and supporters, we will continue to contribute our Dementia Advisors, our nurses, our Helpline and the research centres we fund. Together, let's aim to make Scotland a world-leader in dementia support.

**Henry Simmons**  
Chief Executive

The National Dementia Strategy for Scotland can be found at [www.scotland.gov.uk/Resource/0042/00423472.pdf](http://www.scotland.gov.uk/Resource/0042/00423472.pdf), or call the Dementia Helpline 0808 808 3000 for a copy.

# Trio of **new resource centres** opens

During the summer, Alzheimer Scotland extended its national network of Dementia Resource Centres with new centres opening in Stornoway, Stranraer and Clydebank.

The first of the clutch was the brand new Dementia Resource Centre at 67 Hanover Street in Stranraer. This was officially opened by local MP Russell Brown on Friday 3 May. Sheila Sloan and her mother Jean McNally, who uses the new centre, joined Mr Brown for the ribbon cutting ceremony. Mrs Sloan said "I can't praise the centre highly enough. They go out of their way to make your life easier when you're caring. My mother used to be a great knitter, but it seemed as though her dementia had stopped all that. Then one of the women at the centre got my mum into the knitting club and she's made three cardigans since then. She's reading patterns and everything. It's amazing the change in her. I can't thank them enough for all their help and support to my parents and to me as well."

The newly refurbished Lewis & Harris Dementia Resource Centre was declared open on Wednesday 29 May by HM Lord-Lieutenant of the Western Isles, Sandy Matheson OBE. Located at 18 Bells Road in Stornoway, the centre is the hub for Alzheimer Scotland's services in Lewis & Harris. These include a dementia cafe, a weekly singing group and a Dementia Link Worker who supports people with dementia and their families for the first year after diagnosis. Hugh Smith, a former carer, talked about the benefits of the centre for him: "Before my wife's death earlier this year the centre helped me to understand and come to terms with my wife's illness. It was an invaluable source of information, practical help and unconditional support."



Dementia resource centres open in Stranraer, Stornoway and Clydebank.

The third new resource centre opened in Clydebank on Friday 7 June, during Dementia Awareness Week. West Dunbartonshire Dementia Resource Centre is located at 6-8 Miller Street and has already had a positive impact on the local community. Willie Miller, who is supported by the centre, explained: "I find the centre like a home from home and would say it's in an ideal location. The staff

are very experienced. I have made a lot of new friends that I enjoy afternoon sing songs with. I would recommend it to anyone thinking of coming along." The centre was opened by Provost Douglas McAllister of West Dunbartonshire Council, who added: "The centre is co-funded by the council and has an important role to play as part of our commitment to people with dementia and their carers."

# Under the spotlight - interview with Alex Neil

**In your first year as Cabinet Secretary for Health and Wellbeing, what are your reflections on the progress that has been made since the Scottish Government made dementia a national priority in 2007?**



Following the publication of Scotland's second Dementia Strategy, we asked the Cabinet Secretary for Health and Wellbeing to reflect on the progress made in the past three years and outline how he plans to maintain that progress and build upon it.

I'm encouraged by progress made since we made dementia a national priority in 2007 in key areas such as diagnosis. We established a three year national diagnosis target in 2008, which was achieved nationally and contributed greatly to significant improvements in diagnosis rates. As at March 2012, in Scotland, around 64% of those with dementia were being diagnosed, a similar figure to Northern Ireland and significantly better than England and Wales. This is encouraging but we cannot be complacent and we'll continue to focus on sustaining and further improving diagnosis rates.

**What do you think have been the main success stories from the first Dementia Strategy and what emerged as the main challenges going forward into the next three year strategy?**

The 2010 National Dementia Strategy led to publication of The Standards of Care for Dementia in Scotland and the Promoting Excellence Skills and Knowledge Framework the following year. Implementation of both in tandem has been the bedrock for further improvement since 2011 and will continue to be important. We shared Alzheimer Scotland's view about how important it was to improve service response in general hospitals – that's why we supported Alzheimer Scotland in appointing Dementia Nurse Consultants to NHS Boards across Scotland. Moreover there are now over 300 Dementia Champions –

drawn from the frontline of services - trained and helping to lead and influence change in response to people with dementia at that frontline of care in hospitals and associated care settings.

Improving post-diagnostic support was also a key area in the first strategy and we've worked closely with Alzheimer Scotland and others to lay the groundwork for what is a world-leading national post-diagnostic commitment, which guarantees a year's worth of dedicated support after diagnosis coordinated by a Link Worker for everyone diagnosed from 1 April this year.

I've identified three challenges which we need to focus on over the next three years: offering services which promote wellbeing and quality of life of people with dementia and their families, which also protects their rights and respects their humanity; improving care pathways to ensure they are person-centred; and continuing to embrace the process of redesign and transformation of services to ensure that we deliver services effectively and efficiently.

**At the Dementia Champions graduation in May, you launched a 10 point action plan for acute hospital care for people with dementia which is now part of a new national dementia improvement programme. What do you expect this programme to deliver?**

Our challenge remains to ensure that, when admission to acute general hospitals is unavoidable for people with dementia, they experience, on every occasion, safe, effective, dignified and person-centred care. We've agreed a National Action Plan to support

implementation of the Standards of Care for Dementia in acute care to make sure the current system of hospital care is working and to maximise the impact of the investment over the last two years in the capability and capacity of staff operating in those settings. It will support service transformation and support strategic ownership of this agenda at an NHS Board level. The Action Plan will help focus and coordinate a range of initiatives taken forward over the last two years. The National Dementia Care Improvement Programme will focus on this and other key parts of the strategy, supporting delivery and helping services use key data to drive improvement.

### **How successful do you feel that our joint investment in the Alzheimer Scotland Dementia Nurse Consultant programme has been?**

The last two years in particular have seen significant investment and advances in the capacity and capability of staff in hospitals, including the appointment of Alzheimer Scotland Dementia Nurse Consultants across Scotland as well as the Dementia Champions programme. These initiatives have supported the improvement programmes within NHS Boards in response to the prioritisation given to older people's care by the Deputy First Minister from 2011, the resultant programme of Healthcare Improvement Scotland inspections into older people's care in hospitals, the associated Chief Nursing Officer-led national improvement work and in implementing the Standards of Care for Dementia.

Building on this, the Nurse Consultants will now be key to helping their respective NHS Boards engage with the national action plan on improving dementia care in hospitals.

### **The new Dementia Strategy extends the priority focus to**

### **continuing care environments and mental health services. What approach to improvement do you think is needed in these environments?**

Our focus under the first dementia strategy was on acute general hospitals. However, a strong message from the Dementia Dialogue events was that similar attention in the future needs to be on other inpatient services, including NHS mental health services for people with dementia, continuing care settings and rural community hospitals and in psychiatry of old age wards. While these settings share many of the issues that acute general hospitals face, there are different and additional challenges and it is unlikely that care will always be of the quality required under the Standards of Care for Dementia, nor that staff will meet the expectations in respect of knowledge and skills set out under the Promoting Excellence framework. We are currently developing our approach to tackling these issues; and The Mental Welfare Commission will be considering the application of the Standards in this context as part of its visits programme in 2013-14.

### **The Dementia Strategy sets out 17 commitments. How will the Scottish Government ensure that these commitments will be met and how will they be monitored?**

I wanted a strategy that was ambitious but deliverable. As in the first strategy, we acknowledge that while change and improvement will not be easy we are confident that we are taking the right action nationally to help make real and measurable improvement over time. A national, overarching group will be tasked with implementation and monitoring of the strategy and we have a range of quantitative and qualitative measures and indicators of change and improvement.

This time, as mentioned earlier, I have also set up the National Dementia Care Improvement Programme to support implementation and delivery of key "big ticket" commitments, such as the post-diagnostic HEAT target, the 8 Pillars testing and the improvement work in general hospitals. This programme will provide additional expertise to local services and help free up some time to focus on improvement in integrated community services.

### **We have recently established the Scottish Dementia Research Consortium to work alongside the Scottish research community. How much of a priority do you place on Scottish dementia research becoming a world leader?**

Supporting world-class research into dementia remains a key part of our national approach to dementia. I recognise that people with dementia and their carers have a major role to play in bringing about change in dementia prevention, treatment and care by becoming partners in research. We established the Dementia Clinical Research Network for Scotland in 2008 and funding has been extended to 2014. We'll build on the research achievements of the first strategy - broadening support across a wide range of world class research teams from basic science through to social studies to integrate dementia research by working with and supporting the new Scottish Dementia Research Consortium as it seeks to maximise the impact of and funding opportunities for research in Scotland.

### **In April 2013, you introduced what we believe to be a world first in the form of the post-diagnostic guarantee. How happy are you with the progress made on this so far?**

A diagnosis of dementia can have a huge impact on individuals,

carers and families and the guarantee is there to give people diagnosed from 1 April time and space to access expert services and receive high quality support in a way that meets their needs over the course of a year. During the last 12 months, we undertook a significant amount of work with Alzheimer Scotland and others to test the workforce and resource implications of implementing this HEAT target, including developing resources which will enable services across all sectors to plan for its delivery. It's a three year target, with services expected to be delivering the commitment to everyone newly diagnosed by March 2016. NHS Boards began to collect data from April 2013, so we're still quite early on in this process. A delivery Board, including Alzheimer Scotland, will oversee and monitor delivery of the guarantee and the National Dementia Care Improvement Programme will support its delivery.

### **What are the key lessons so far from the three Dementia Demonstrator sites and how might these be applied to the planned integration of health and social care?**

We were initially going to support one site but our ambitions grew when we saw the level of enthusiasm by local partners and the quality of applications. We know also that there are many other examples of local whole-system improvement. The Dementia Demonstrator project's full evaluation will report next January but an interim report this year showed positive messages about the impact of the project in helping local partnerships work together to design and implement local strategies which adopt whole-system approaches to address the demographic challenges of dementia now and in the future. I anticipate that the lessons for integration in the full evaluation will echo these interim findings in respect of the need to address

whole local systems of dementia care so that we ensure that we deliver better outcomes for more people with the same resource.

### **We believe that our 8 Pillars model of community support is an essential way of ensuring integrated care for people with dementia in the mid to later stages of the illness. What do you see as the key challenges for people going through these later stages of dementia?**

I was pleased that we were able to ask people with dementia and their families and service providers what they thought of the 8 Pillars model as part of last year's Dementia Dialogue. Views were generally positive and we're committed to working with Alzheimer Scotland as well as COSLA\* and ADSW\* to test and evaluate the model as part of the new strategy. We've invited local partnerships to a selection process.

I know how vital it is that people have good quality and seamless care and support as their symptoms advance and they begin to need more intensive support. As the 8 Pillar model illustrates, people not only need interventions to tackle the symptoms but also coordinated and holistic attention to their overall health, wellbeing and quality of life and that of their carers. People have their own individual experience and challenges but the 8 Pillars can be a means by which all individuals are comprehensively assessed and supported as their dementia becomes more challenging. We'll evaluate the model over the course of the new strategy.

### **We are pleased that you have announced an independent review into NHS continuing care funding. What is the remit of the review and when do you expect it to report?**

I have asked the review to do five things: it will assess whether our

guidance was being followed, and a consistent approach was being taken across Scotland; it will confirm whether record keeping is adequate, and decisions made are being clearly and appropriately articulated to all concerned; it will assess whether improvements are needed to raise awareness of NHS Continuing Healthcare amongst professionals and general public; it will assess whether the decision making process is based on clinical need rather than financial circumstances; and, finally, it will consider whether an independent appeals process is required.

I expect the review to report to me in January 2014.

### **Finally, is there a key message you would like to send out to our readers and members?**

I value the opportunity to speak to your readers and to re-assert how important the dementia agenda continues to be for me as Health Minister. Working closely with Alzheimer Scotland and with the Scottish Dementia Working Group and the National Dementia Carers Action Network is invaluable and I look forward to continuing to work with you to ensure that people with dementia and their families experience the highest quality of care on every occasion.

\*Confederation of Scottish Local Authorities Association of Directors of Social Work

# NHS continuing care

*NHS continuing care is a package of care arranged and funded wholly by the NHS. It is designed to meet the needs of people who have complex health care needs arising from any illness or disability but who do not need to be in an acute hospital bed to have their health care needs met. Only those who meet the eligibility criteria are entitled to NHS continuing care. For those who do qualify, continuing care can be provided in a hospital, hospice, care home or at home.*

A recent BBC Scotland investigation highlighted that many people with dementia may be paying for care which should be provided free of charge through NHS continuing care. The investigation also found that the number of people who qualified for this support had fallen significantly since 2009.

The report also highlighted that many people were not told or given any information about NHS continuing care, how to get an assessment, or given a proper explanation about why they did not qualify.

In response to the issues raised by the BBC, Alex Neil, Cabinet Secretary for Health and Wellbeing, indicated that the Scottish Government would look at any case where people may have been wrongly refused or not told about NHS continuing care. The Cabinet Secretary also announced an independent review into NHS continuing care in Scotland - see page 6 for the remit of that review.

## **Getting an assessment**

If you think that you or someone you care for is entitled to NHS continuing care you can ask a member of the hospital care team for an assessment. If you are not in hospital, you should ask your GP. The assessment must take account of your views and those of

your carer and should be carried out by a doctor and others such as a nurse, social worker, or a specialist such as an occupational therapist. You should be given a copy of the assessment and a full explanation of the decision.

## **What if I don't qualify?**

If you do not qualify, the NHS still has a duty to meet any health care needs you have. The assessment should also identify any social care needs that you have. These should be arranged by your local authority. Depending on your needs, financial resources and your age, you may have to pay towards any social care services.

## **What if I disagree with the decision?**

You can ask for a review of the decision with the team or person who made the decision within 14 days. The NHS board should appoint another professional of the same level of expertise to carry out the review.

If, after the review, you remain unsatisfied you can use the NHS complaints procedure. This can only look at whether the procedure was correct. If it wasn't, the process may need to be repeated. If you still disagree with this decision you can complain to the Scottish Public Services Ombudsman.

If you think that you or someone you care for may have been entitled to NHS continuing care in the past and were not told about it or think it was wrongly refused, you should write in the first instance to the Chief Executive of the NHS Board responsible. You can find the address of the NHS Board in your local phone book, or contact the Dementia Helpline on 0808 808 3000 for a list of Board addresses.

# 8 Pillars of Community Support

The Scottish Government, in partnership with Alzheimer Scotland, the Convention of Scottish Local Authorities (COSLA), and the Association of Directors of Social Work (ADSW), are taking forward the commitment in the dementia strategy to test and evaluate Alzheimer Scotland's 8 Pillar Model of Community Support. The Scottish Government has written to the Chief Executives of all NHS Boards and Local Authorities inviting them to express an interest in becoming one of four test sites.

The "8 Pillars" model provides an integrated approach to care and support by bringing together the full range of health and social care interventions to support people with dementia and their carers. It provides families with a named dementia practice coordinator who will work with them to coordinate the care and support they need from the full range of health, social care and community resources available.

This work will enable the Scottish Government and its partners to evaluate the effectiveness of the model, make any necessary revisions to it, produce implementation guidance and tools to support the roll out of integrated dementia care and support and, ultimately, decide whether to adopt the model for the next dementia strategy from 2016.

## **Jim Pearson**

Deputy Director – Policy  
Alzheimer Scotland

# Dedicated fundraiser receives **British Empire Medal**



Barbara Barnes, who has been a supporter of Alzheimer Scotland for many years, was honoured with a British Empire Medal for her charity work in this year's Queen's Birthday Honours list. Barbara, who is from Alexandria, has taken part in countless fundraising challenges for Alzheimer Scotland, including adrenaline-fuelled zip slides, abseils and sky-dives. Her proudest fundraising event was a wing walk (pictured), when she asked friends to make a donation to Alzheimer Scotland in lieu of presents for her 70th birthday. Commenting on receiving the medal, Barbara said: "I'm very honoured to be named, if a little embarrassed, as there are many people who do so much. I was very surprised when I got the letter about six weeks ago to tell me I had been nominated." Although Barbara also raises funds for other charities, she mainly supports Alzheimer Scotland as her parents and mother-in-law were all diagnosed with Alzheimer's disease.



# Recognised for **Excellence**



Julie Miller and Kate Fearnley with Alzheimer Scotland's Recognised for Excellence Award.

On 17 June Alzheimer Scotland was delighted to receive a 3 star Recognised for Excellence Award at the Scottish Awards for Business Excellence in Glasgow.

Recognised for Excellence is a Europe-wide scheme that promotes

organisational excellence. Winning the award involved a rigorous application process which was led by Julie Miller of Alzheimer Scotland's Development Team. This was followed by an in-depth assessment by Quality Scotland, who looked at every aspect of the organisation and talked to a cross-section of staff.

Kate Fearnley, Alzheimer Scotland's Deputy Chief Executive, said: "We're really pleased to have received this award, which is a recognition of the way staff and volunteers across Alzheimer Scotland are so tremendously committed to our mission of not letting anyone go through dementia on their own, and so determined that our services and our other work are of the highest possible quality. It recognises every dimension of what we do, both in our public-facing work and behind the scenes, so it is a real reflection of everything that goes to make up Alzheimer Scotland."

## **West Highland Way fundraiser**

Jim Collins and his brother Philip raised over £750 by walking the West Highland Way for Alzheimer Scotland between 22 and 29 May in support of their mother, who was recently diagnosed with vascular dementia.



## **Perth Branch celebrates 25 years!**

Members of Alzheimer Scotland's Perth Branch, their families and friends, enjoyed a day of music and dance at the Lovat Hotel on 15 June to celebrate their 25th anniversary.



Photo courtesy and copyright of D C Thomson & Co Ltd.



# Motherwell shop supports Dementia Awareness Week



During this year's Dementia Awareness Week in June, Boots in Motherwell's Brandon Parade used one of its windows to promote dementia awareness and set up an in-store display with leaflets and information from Alzheimer Scotland and the NHS. Anyone who had concerns about dementia was signposted to the local Dementia Resource Centre. Boots organised the event in support of the Dementia Friendly

Communities work taking place in Motherwell. Ten staff from Boots also attended a series of three awareness sessions for retailers, learning more about dementia and how to support people who came into the store looking for information. The sessions were organised by Sandra Shafii, AHP Dementia Consultant, and Arlene Crockett, manager of the Lanarkshire Dementia Resource Centre.

## Save the date!

Our annual Staff and Members Conference, including the Annual General Meeting and Awards Ceremony, will take place on Friday 1 November 2013 at Murrayfield Stadium, Edinburgh. For the first time the programme will include workshop sessions giving staff and members an insight into other areas of activity, key projects and developments. It is hoped the day will be stimulating, engaging and participative.

Members will have received a letter of invitation and registration form enclosed with this magazine. The letter from our Convener, John Laurie, also gives a summary of the proposed changes in governance arrangements for the organisation, as well as the new draft Articles of Association. If you are a member and would like to attend the conference and AGM, please complete and return the enclosed registration form. If you have any queries, please email [agm@alzscot.org](mailto:agm@alzscot.org).

# Don't forget!

Use the join us card from the last edition of the magazine, or send the person's name and address to us by email, post or phone quoting 'free membership'

\*Membership is free for one year

Email: [info@alzscot.org](mailto:info@alzscot.org)  
Phone: 0131 243 2453

...to sign up someone you know for free Alzheimer Scotland membership\* before 30 September.



# Alzheimer Scotland Memory Walk 2013

Dalkeith Country Estate, Edinburgh  
Saturday 21 September, 11am – 4pm



## Memory Walk & Bupa Memory Mile



Join us for a fun, family day out to raise funds for Alzheimer Scotland on World Alzheimer's Day. Enjoy a gentle 5.6k walk that's suitable for all ages and abilities.

**To register:**

phone 0845 260 0789  
visit [www.alzscot.org/walk2013](http://www.alzscot.org/walk2013)  
or email [events@alzscot.org](mailto:events@alzscot.org)

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# Dementia assistance dogs start work



Two specially-trained dogs have become the first assistance dogs in the UK to help people with dementia. Kasper, a Labrador, and Oscar, a Golden Retriever, are part of a project to investigate how a dog may bring benefits to people with early-stage dementia.

The Dementia Dog project was conceived by students at Glasgow School of Art's Product Design department, then developed by a partnership between Alzheimer Scotland, Dogs for the Disabled and Guide Dogs Scotland. It started in 2012 and combines the skills of the four organisations, with financial support from the Scottish Government and the UK Design Council. Both dogs have been trained to offer practical assistance and help reduce social isolation and anxiety levels, some of the problems experienced by couples where one partner has dementia. A further two dogs have already begun their training.

Oscar joined the Dementia Dog project having been withdrawn from guide dog training, whilst Kasper came straight from the Dogs for the Disabled socialisation scheme. As puppies they spent their first year with experienced volunteers, where they learned to be well-behaved and well-mannered young dogs. At just over a year old they moved into the Guide Dogs Training Centre at Forfar, where they were trained for their new role with the specialised help of staff from Dogs for the Disabled, who are based in Banbury, Oxfordshire.

In March this year, Oscar and Kasper went to live with couples Frank and Maureen and Ken and Glenys from Angus. Maureen and Ken were both recently diagnosed with early stage dementia and both couples were already receiving support from Alzheimer Scotland. Oscar and Kasper have settled into their new homes and are already making



a positive impact. Both dogs have been trained to fetch medicines when the reminder alarm goes off. They can also take items between the two couples and have been trained to help wake a person up.

For both couples, having an assistance dog has provided a reason to go out for regular walks to the park together – a great way of meeting people and keeping in touch with the world around them. The dogs are also proving to be great stress-relievers at home, where the couples say that they feel more motivated. The carers are spending less time giving reassurance to their partners because the dog gives a calming new focus for the person with dementia. Carer Glenys says “Kasper has given us our lives back”, while Frank, who cares for Maureen, says “We can’t imagine going back to what it was like before we got Oscar”.

Joyce Gray, Alzheimer Scotland's Deputy Director of Development, added “Dementia Dog has had a truly wonderful impact on the families involved and we are delighted to have been part of this ground-breaking project. It's also been a great example of partnership working.”

# We stitched the pitch!



Our slogan “Yes we can – together” became “Yes we did – together” on a scorching Saturday in June as we well and truly stitched the pitch at Hampden, Scotland’s National Stadium. This was the grand finale of an incredible four-year project to fill the pitch at Hampden with beautiful quilts. Thanks to the support of our many wonderful volunteers and partner organisations, over 5,000 quilts were laid across the pitch. They were donated by generous quilters from across Scotland and England, and even as far afield as America and Australia. This project really did inspire a nation of quilters to take up the mantle and make a quilt (or three) to raise awareness of dementia and the impact it can

have on the lives of those affected by the condition.

The project all began when Ann Hill, Alzheimer Scotland’s Quilter in Residence, took up the challenge laid down by Robert Craig, Chairman of the Scottish Football Museum, to make a quilt the size of the pitch. Ann informed Mr Craig that ‘quilters can do anything’ and with the achievement of this feat we are inclined to believe her!

Not only did quilters from across the globe create quilts for this project, they also allowed us to sell them to raise money for dementia services across Scotland. To date we have raised over £9,000 through this project – with well over 4,500 quilts still to sell. Each quilt comes

with a certificate to show that it belonged to the Hampden Quilt Challenge and that all proceeds will go directly to supporting people with dementia.

We must thank our wonderful Quilter in Residence, Ann Hill, for all her support, energy and enthusiasm in starting this project and encouraging so many quilters to get involved. It would not have happened without her persistence and motivation. She rallied support from quilters, volunteers and even celebrities such as Billy Connolly, Craig Brown and the stars from Mrs Brown's Boys. Each of them have a quilt specially made by Ann which is now signed and ready to be auctioned to raise even more funds to support the work of Alzheimer Scotland.

### Own a part of history

We are convinced that this will never happen again and owning your own Hampden Challenge quilt will be something to share with your friends and family for years to come. With over 4,500 quilts to choose from, there is something to suit all tastes. A selection of quilts is available to buy from our website, as well as from our charity shops and other selected venues across Scotland.

[www.alzscot.org/shop/quilts](http://www.alzscot.org/shop/quilts)



*"I've never seen anything like it. I'm so proud to have been a part of it and I'd like to say a huge thanks Ann Hill and all the amazing quilters and volunteers who made it all possible."*

**Rachel Laming**

*"It was an amazing day. The huge variety of quilts, and the enthusiasm of the organisers made it an event which will live long in the memory of everyone who was there."*

**Robert Craig**

*"It was a delight to witness the fulfilment of the hopes and desires of Ann and her friends on such a wonderful day with the glorious weather topping the occasion."*

**Colin Lobban**

*"An enormous thank you to all who contributed quilts, to those who helped along the way and to the volunteers who turned out on a wonderfully sunny day to help me make my dream a reality."*

**Ann Hill**

# The Aberdeen GP Dementia Scholarship 2012–2013



**Ten GPs from Aberdeen recently completed a scholarship programme to enhance their skills in caring for patients with dementia. The programme was organised by Dr Sridhar Vaitheswaran, Consultant Old Age Psychiatrist, NHS Grampian, and Dr Peter Kiehlmann, Clinical Lead at Aberdeen City CHP and a GP at Danestone Medical Practice.**

The Dementia Scholarship has been modelled on a highly successful Diabetes Scholarship that has been running in Grampian since 1999. Before this was introduced, GPs had little confidence in caring for people with diabetes. Now they play a much more active role in the management of the condition. The Dementia Scholarship is designed to help them make the same shift towards managing dementia better in primary care.

The GPs who took part in the scholarship experienced many aspects of the dementia pathway first-hand, including diagnosis, active ageing, carer support, drug and non-drug management and anticipatory care. It involved input from patients, carers, social work staff and the third and private sectors, as well as many hospital-based staff.

GPs were targeted because of the vital role they play in coordinating care and support for people with dementia in the community. Nearly two-thirds of people with dementia in Scotland live in their homes in the community, so GPs often have considerable contact with

them. The topics that made up the scholarship were selected by the participants, and many linked into the National Dementia Strategy. They included:

- timely diagnosis and carer support
- encouraging active ageing and dealing with the 'worried well'
- patients with dementia who live in their own homes – support, placement issues, carer support and safety
- patients with dementia in care homes – anti-psychotic prescribing, non-pharma management of behaviour, community mental health teams and prescribing in dementia
- legal issues – assessing capacity, power of attorney and guardianship.

Speakers at the group meetings included a person with dementia, a carer, consultant old age psychiatrists, community psychiatric nurses, occupational therapists, an Alzheimer Scotland Dementia Nurse Consultant, a solicitor, specialist social workers, a telecare expert and members of staff from a care home.

Feedback from participants was very positive, with comments such as "All areas of management of dementia improved" and "Increased confidence in dealing with earlier diagnosis". The organisers believe the programme can help integrate health and social care, enabling services to deliver high quality person-centred care and hope to build on the success of the scholarship by making it available to other GPs in the future.

## Flying start for Shetland Branch



Heather Fisher, Cecil Smith, Ruth Newbold, Geoff Clark, Rhona Anderson and Ann Williamson.  
Photo: Dave Donaldson/Shetland Times

The Shetland Branch of Alzheimer Scotland was officially established in December and is now actively working on a range of projects with the local community. Ann Williamson, Dementia Advisor for the Shetland Isles, arranged a public meeting in November to discuss setting up the branch. Over 20 people attended, including Alzheimer Scotland's Regional

Manager, Fiona Roberts, and the local Dementia Services Nurse Manager and Dementia Specialist Clinical Nurse.

"I became Dementia Advisor for Shetland in January last year and it quickly became clear there was huge interest in the work of Alzheimer Scotland locally", explains Ann. "The meeting

in November gave people an opportunity to hear about what was happening in the area, as well as our aspirations for the development of services in Shetland. There was fantastic support from the local community and a committee was formed that night. The new branch is a great way of helping support the 173 people in the islands with a diagnosis of dementia."

The Shetland Branch was given the official seal of approval by Alzheimer Scotland's governing Council in December. So far it has been instrumental in supporting the Dementia Café, as well as helping with activities during Dementia Awareness Week. The branch's first fundraising event was a Sunday Tea which raised almost £800 in an afternoon.

The branch is chaired by Heather Fisher, with Cecil Smith as vice-chair, Janice Drummond as Treasurer and Rhona Anderson as secretary.

To get involved or find out more phone 01595 693686 or email [heather@rae.shetland.co.uk](mailto:heather@rae.shetland.co.uk).

## Short Breaks Fund creates 'time to live'



Helen was able to enjoy a short break in Paphos with her son Gordon.

In October last year Alzheimer Scotland received £31,200 from the Short Breaks Fund to create 60 much needed breaks for people with dementia and those who

love and support them. The aim was to give them 'time to live', helping them to reduce stress and enjoy really innovative breaks. The scheme gives power back to those who don't always have the funds or opportunity to do something most of us take for granted: planning the break we need at the time that suits us.

70 breaks later we applied for more funding, receiving another £6,380, and by the time all the money had been allocated we had provided an amazing 82 breaks. The variety of things people chose to do was stunning: some at home, some abroad, some alone and some together! All were welcome opportunities to make life

truly better for those affected by dementia.

Our staff and volunteers spread the word about the breaks far and wide, and many of those who applied were not previously known to our services. By circulating flyers to other professionals and groups we ensured that many people got to hear about the funding.

The pictures and feedback forms we have received pay testament to the gratitude of those who were able to access the fund. We have applied for more funding from next year's Short Breaks Fund and will hopefully be able to tell you about more breaks taken by people with dementia and their loved ones next year!

# Making community pharmacies dementia-friendly



*Sally Arnison has worked in community pharmacy for 19 years, most recently co-running the Barnton Pharmacy in Edinburgh. In June she spoke at a conference in Glasgow about a checklist she has developed to make her pharmacy more dementia-friendly. I called in to find out more.*

Over the past 10 years, Sally has seen a shift in her own attitude towards people with dementia. Previously she and her colleagues were aware of people in the community who may have had dementia, but tended to deal with each situation as it arose, rather than trying to do anything really co-ordinated to help. “We were failing our patients”, says Sally.

## Checklist for Dementia Friendly Community Pharmacies

Sally’s checklist encourages community pharmacies to evaluate their existing knowledge of dementia alongside other factors including local demographics and their links with local networks, such as Alzheimer Scotland and GP practices. She is aware of around 50 people with a diagnosis of dementia who regularly use the pharmacy, but reckons that there are probably at least as many people again without a

diagnosis. Approaching someone whom she suspects might be developing dementia can involve gently broaching the subject with a question such as “Are you worried about your memory?” She also has a good relationship with the local GP surgery where one GP in particular is very focussed on services for older people. But sometimes she needs to have frank conversations with patients’ family members where there are concerns.

As part of her approach to becoming dementia-friendly, Sally asked our Dementia Advisor for Edinburgh, Teresa Straczynski, to deliver some awareness training to pharmacy staff. Open days were then held in the pharmacy where Teresa was able to meet with patients in the pharmacy’s consulting room. Since then, a Dementia Café has started in Cramond Kirk Hall on the first Monday of the month when people can meet up with Teresa instead of in the pharmacy. Information about dementia, including our Dementia Helpline number, is displayed in the pharmacy.

Sally is very clear that pharmacists don’t need to be specialists to give greater support to families living with dementia. She sees her role as

helping “join the dots” with other professionals and organisations to make sure no-one slips through the net. “There are still patients going through the system where no-one knows the full picture and that can lead to people’s difficulties not being picked up and addressed”.

## Medication management

When it comes to managing medication, Sally is adamant that each person’s needs should be individually assessed and monitored on an ongoing basis. It’s not enough to hand over a reminder box and hope for the best. As some people prefer to get their medication delivered, Barnton Pharmacy’s delivery driver has been trained in Medicine Compliance Assessment (MCA) and can report any problems or changes he observes on his delivery round.

Multiple medications can cause unexpected interactions, and the NHS has recently published guidance for anyone who receives four or more medicines (known as ‘polypharmacy’). Sally has recruited a student pharmacist to investigate polypharmacy, prioritising those patients who use medication reminders like Dosette boxes.

Sally would like to see greater uptake of the NHS Chronic Medication Service (CMS) for patients with long-term conditions. Anyone registered with a doctor in Scotland who receives regular prescriptions for a long-term condition can register with a pharmacy for this service. The pharmacist will then ask about the medications being taken, carry out a risk assessment and discuss any difficulties being experienced, including problems with remembering to take medication. If the pharmacist and the patient think it is necessary, a care plan for managing medication will be developed and regularly monitored by the pharmacist.

**Maureen Thom**  
Information Manager  
Alzheimer Scotland



# New report on specialist support for families, carers and communities



## LOTTERY FUNDED

Alzheimer Scotland has published a new report called *Specialist dementia support for families, carers and communities*. This summarises findings from a research project in the NHS Highland area funded by the Big Lottery. NHS Highland, Argyll & Bute Council and Highland Council worked in partnership with Alzheimer Scotland on the project, and the research involved 137 families living with dementia and 100 health and social care staff.

People with dementia living in remote and rural areas can

experience particular challenges, including problems getting the information they need and difficulty accessing care at home. The new report describes ways of helping people to keep well and stay active, as well as creative options for providing advice and support in remote and rural areas. Its recommendations have been used to inform strategic planning for future dementia services and commissioning in both local authority areas.

A number of projects are already underway to improve access to care and support for families affected by dementia in the Highlands. These include:

- the introduction of seven Dementia Link Workers to support people after a diagnosis of dementia in the Highland Council area, building on the

- success of the Link Worker initiative in Argyll & Bute
- the appointment of an Alzheimer Scotland Dementia Nurse Consultant
- training of a network of Dementia Champions to help improve standards of care in acute hospitals
- publication of a series of new dementia resource guides.

Alongside the research project, Alzheimer Scotland also produced eight resource guides for families living with dementia in NHS Highland. These cover different areas of the region, and feedback from carers and healthcare staff has been very positive. One carer said "I think the guide is really excellent and very well presented for those caring for loved ones with dementia at an earlier stage.". A care worker described it as "simple, effective and easy to use".

To download the project report visit [www.alzscot.org/carers-research-project](http://www.alzscot.org/carers-research-project). To download the guides visit [www.alzscot.org/familiesguide](http://www.alzscot.org/familiesguide).

## Silver award for Strathmore Dementia Information Cafe



Fiona Miller, Pam McKenzie, Rosemary McLean, Kath McGregor, Rachael Ferguson, Councillor Peter Barrett, Fiona Matthews and Monika Mill

The Strathmore Dementia Information Cafe, based in Blairgowrie, recently collected a silver award at Perth & Kinross Council's Securing the Future Awards 2013. The café is a joint project, run in partnership with Alzheimer Scotland, PKC Strathmore Day Opportunities and NHS Strathmore Dementia Service.

The drop-in café provides information, support and advice to people who are worried about their memory or living with a diagnosis of dementia and, along with their family and friends, gives people the opportunity to meet others living in similar situations over tea/coffee in an informal setting. There is also the opportunity to have a

confidential memory test by trained nurses, which is unique in the Perth and Kinross area.

Now in their fifth year, the Securing the Future Awards were set up to recognise council services that demonstrate particularly high levels of achievement. The Strathmore Dementia Information Cafe won silver in the Promoting Sustainability category.

Fiona Matthews, Dementia Advisor for Perth & Kinross, congratulated the team running the cafe, saying "This has been a great opportunity for partnership working between different organisations and local volunteers, to give people living in a more rural locations the opportunity to get together for a chat and to get access to information and support, which can enable them to live with their diagnosis of dementia in their communities and to raise awareness of dementia in these communities".

# 'Very good' Care Inspectorate gradings for Alzheimer Scotland services

Alzheimer Scotland provides services for people with dementia across the whole of Scotland. These services play a vital role in ensuring that as many people as possible with a diagnosis of dementia can access high-quality, appropriate support in their local area.

Our services are regulated by the Care Inspectorate, which monitors them to ensure they are of a high standard. In April 2008 the Care Inspectorate introduced a grading system which gives services a score based on a range of different 'quality themes'. Each theme is graded from unsatisfactory (1) to excellent (6).

*"The service is person centred and demonstrates a strong commitment to promoting choice and independence."*

## Fife Service

We work hard to ensure that our services are as good as they possibly can be, and regularly talk

to people with dementia and their carers to find out what support they would like us to provide. However, the Care Inspectorate reports provide both the people who use our services and Alzheimer Scotland with an independent assessment of how we are doing.

During the first six months of 2013, nine of our services were inspected, and we are delighted to report that all of them received scores of 5 (very good) or 6 (excellent) on all aspects of their work. This is a tremendous endorsement of the hard work of our staff and volunteers, who provide such a wide range of services right across Scotland all year round.

On 3 June the *Greenock Telegraph* published an article entitled 'Care centre facility given glowing report' in the wake of the Care Inspectorate's review of the Inverclyde Dementia Resource Centre. The centre scored a maximum 6 out of 6 on all four quality themes, and was described by the inspectorate as having 'created an excellent person centred approach to delivering its

service' with 'service users at the heart of all that they do'.

*"Service users and carers whom we spoke with described all the staff as being exceptionally kind and caring as well as supportive and approachable."*

## Ayrshire Service

While positive Care Inspectorate gradings are a great endorsement of the work we do, they are only one way of measuring standards. We constantly gather feedback on our services to make sure that they are meeting the standards we aspire to, and the most important source of feedback is those who use them. All our services regularly survey both people using the service and carers. Overall, 409 people with dementia and 831 carers responded this year. Using a scale similar to the Care Inspectorate, 91% of people with dementia and 85% of carers rated their service as very good or excellent. If you would like to tell us how we can improve – or share a positive experience – please contact your service at any time, or email [info@alzscot.org](mailto:info@alzscot.org).

*"The day centre was warm and welcoming and staff were professional, motivated and courteous. The home support service was also praised for its flexibility and quality of care."*

## Renfrewshire Services

### Alzheimer Scotland Care Inspectorate gradings, January–June 2013

Name of service	Quality of care & support	Quality of environment	Quality of staffing	Quality of management & leadership
The Elm Centre – Dumbarton	5	5	5	5
East Renfrewshire Services	6	N/A	5	5
Inverclyde Services	6	6	6	6
Renfrewshire Services - Paisley	5	6	5	5
Ayrshire-wide/The Rowallan Centre – Kilmarnock	5	N/A	5	5
Moray Services	5	N/A	5	5
Dundee Services	5	6	6	5
Mid & East Lothian Services	6	N/A	6	6
Fife Services	5	N/A	5	5

A score of 5 corresponds to 'very good'. A score of six means 'excellent'.

# New guide for carers and care staff to make communication and mealtimes easier



Linda Prevett, Rebecca Kellett and Fiona Murchie from the Speech and Language Therapy Adult Team, NHS Dumfries and Galloway

A new guide from NHS Dumfries & Galloway will help carers and care staff communicate more effectively with people with dementia, as well as making mealtimes more enjoyable and helping to improve nutrition and wellbeing.

The Communication and Mealtimes Toolkit has been compiled by Rebecca Kellett, Specialist Speech and Language Therapist with NHS Dumfries & Galloway. There are two parts to the kit: one focusing on communication and the other on eating and drinking. Topics include preparing for mealtimes; non-verbal communication; posture for eating and drinking; and what to do when someone is not eating and drinking enough. The guide is based on the principle that good communication is essential to caring for a person with dementia, and that special techniques and strategies are needed to ensure the person receives adequate nutrition.

The toolkit includes an eating and drinking care plan that can be used to record important information

such as a person's likes and dislikes, and any factors that might make them unable or unwilling to eat their food. The information can be used by care staff who may not always know the person well to ensure their mealtimes are stress-free and enjoyable. Many of the tips and suggestions in the toolkit are also relevant to family carers, and can help them support the person they care for more effectively.

Printed copies of the toolkit have been sent to all wards, community and cottage hospitals and care homes in Dumfries & Galloway. In addition, 100 copies have been supplied to Alzheimer Scotland in Dumfries and Galloway to distribute to carers.

You can download a free PDF of the toolkit by visiting [www.nhsdg.scot.nhs.uk/Departments\\_and\\_Services/Speech\\_and\\_Language\\_Therapy/Adult\\_SLT/Adult\\_SLT](http://www.nhsdg.scot.nhs.uk/Departments_and_Services/Speech_and_Language_Therapy/Adult_SLT/Adult_SLT). Printed copies are available for £10, including UK postage, by emailing [Dumf-uhb.speechlangtherapy@nhs.net](mailto:Dumf-uhb.speechlangtherapy@nhs.net) or phoning 01387 241422.

## Richmond House Memories Day

The residents, staff, families and volunteers of Richmond House in Crieff held a 'Memories Day' as part of Alzheimer Scotland's Dementia Awareness Week. The day included a cream tea and concert with the theme of Music through the Decades. Prior to the event, residents at Richmond House had also been busy making lots of craftwork to be sold on the day. The grand sum of £356 was raised and presented to Fiona Matthews, Alzheimer Scotland's Dementia Advisor for Perth and Kinross.



## Alzheimer Scotland funds postgraduate scholarships

We are delighted to announce that Alzheimer Scotland is now funding scholarships at both Edinburgh and Stirling Universities. The scheme is part of our ongoing commitment to improving dementia-focused education and training in Scotland. Scholarships are available to Scottish domiciled students for postgraduate study in dementia-related fields. As part of the scholarships, Alzheimer Scotland will engage with students, who will be offered membership of the organisation and encouraged to participate in online activity through social media, online forums, live chat and blogs. For details of courses offered by both universities visit [www.ed.ac.uk](http://www.ed.ac.uk) and [www.stir.ac.uk](http://www.stir.ac.uk).



THE UNIVERSITY of EDINBURGH



UNIVERSITY OF STIRLING

# Welfare reforms: a summary of what has changed

*In the winter 2012 edition of Dementia in Scotland we wrote about some major changes to benefits that were due to be introduced in 2013. This article provides an update on these changes.*

If you are affected and you need more information, 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](http://www.cas.org.uk)). Alternatively, your local authority may provide a welfare rights service and contact details should be available on their website.

## Universal credit

From October 2013, universal credit will replace means-tested benefits and tax credits for people of working age. Universal credit will replace:

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

People already in receipt of these benefits and tax credits will transfer to universal credit on a roll-out basis from spring 2014. It is expected that all new claims for universal credit will be made online.

Universal credit will be paid monthly. Any adjustments resulting from a change of circumstances will come into effect from the following month. Universal credit will not be paid if savings or capital exceeds £16,000.

Some people receiving universal credit will be required to agree to a 'claimant commitment' which places certain conditions on their

entitlement. This will not apply to carers or people who are unlikely to be able to return to work.

You can find out more about universal credit at: [www.gov.uk/universal-credit](http://www.gov.uk/universal-credit)

## Personal independence payment

Personal independence payment (PIP) replaced disability living allowance (DLA) from June 2013. This means that anyone who would previously have applied for DLA now needs to apply for PIP.

If you are currently in receipt of DLA you shouldn't be affected by PIP until 2015 or later, but there are some exceptions. You will be asked to claim PIP if after October 2013:

- there is a change in how your condition affects you
- your current award of DLA is due to end.

Unless either of these happens, you don't need to do anything. You will get a letter in 2015 or later inviting you to apply for PIP. The Department for Work and Pensions (DWP) have said that anyone who does not respond

to the letter will be contacted by phone to remind them to apply. If someone is unable to manage their own affairs, the DWP will contact their representative e.g. power of attorney or appointee. Anyone acting as power of attorney or guardian should ensure that the DWP has their details. Failure to respond to the invitation to claim PIP will result in DLA being withdrawn.

Note: if you currently receive DLA and reached the age of 65 or over on 8 April 2013, you will continue to receive DLA and don't need to do anything as long as you still meet the qualifying conditions.

PIP will have two components; daily living and mobility. The table below shows the activities that make up each component and the range of points that could be awarded.

Each component will have two rates;

- standard rate
- enhanced rate.

Points will be awarded to reflect the difficulties a person has with each activity. Claimants have to score at least 8 points to receive the standard rate, and at least 12 points for the enhanced rate.

Daily living

- standard rate: £53.00
- enhanced rate: £79.15

Daily living activities
1. Preparing food (0–8 points)
2. Taking nutrition (0–10 points)
3. Managing therapy or monitoring a health condition (0–8 points)
4. Washing and bathing (0–8 points)
5. Managing toilet needs or incontinence (0–8 points)
6. Dressing and undressing (0–8 points)
7. Communicating verbally (0–12 points)
8. Reading and understanding signs, symbols and words (0–8 points)
9. Engaging with other people face to face (0–8 points)
10. Making budgeting decisions (0–6 points)
Mobility activities
1. Planning and following journeys (0–12 points)
2. Moving around (0–12 points)

## Mobility

- standard rate: £21.00
- enhanced rate: £55.25

Once someone has applied for PIP, they are likely to be asked to attend a medical assessment. A company called ATOS has been awarded the contract for carrying out the assessments. The assessment will be completed by a health professional. People attending an assessment can be accompanied by a family member or representative.

The DWP will make the final decision on who is entitled to PIP. Someone who is currently receiving DLA will not necessarily qualify for PIP. If you apply for PIP and are turned down, you can challenge the decision and we recommend that you talk to an expert benefits advisor for advice on this.

A carer can claim carer's allowance if the person they care for receives either rate of the daily living component.

You can find out more about personal independence payment at: [www.gov.uk/pip](http://www.gov.uk/pip)

## The Scottish Welfare Fund

The Scottish Welfare Fund was introduced in April 2013 to replace social fund crisis loans and community care grants which were previously administered by the DWP. The new scheme will be delivered by local authorities and will provide two types of grant:

- crisis grants
- community care grants.

To qualify for a payment a person must usually be in receipt of one of the following:

- income support
- income-based jobseekers allowance
- employment and support allowance (income related)
- pension credit.

### Crisis grants

A crisis grant can be awarded to meet expenses that have arisen due to an emergency or a disaster e.g. loss of money, serious fire or flood.

### Community care grant

A community care grant can be paid to:

- help someone remain in the

community instead of going into care

- help a carer move closer to the person they are caring for
- help someone re-establish themselves in the community following a period in care
- help ease exceptional pressures caused by illness or the breakdown of a relationship.

The help you receive will depend on the particular difficulties you face. The help could be in the form of money, a type of voucher or an item e.g. furniture or a cooker.

### Applying for a grant

You will have to request an application form from your local authority. Payments are discretionary and are based on individual circumstances. It is a good idea to seek the help of a benefits expert to complete the form and to challenge a decision to refuse payment.

You can find out more about the Scottish Welfare Fund by visiting your local authority website or at: [www.scotland.gov.uk/Topics/People/welfarereform/scottishwelfarefund](http://www.scotland.gov.uk/Topics/People/welfarereform/scottishwelfarefund)

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## Niemann-Pick Diseases – a group of rare illnesses affecting children

*Many different illnesses can cause dementia-like symptoms, but most people are only aware of the most common ones such as Alzheimer's disease. In general, we tend to think of dementia as something that affects older adults, although there are a variety of rare illnesses that can cause symptoms of dementia in children.*

The Niemann-Pick Disease Group (UK) is a charity that raises awareness of, and provides support to, anyone who is affected by Niemann-Pick Disease (NPD). Their aim is to make a positive difference to the lives of those

affected by NPD and their families, through the provision of care and support, accurate information and the promotion of relevant research.

Niemann-Pick Diseases are a group of rare genetic diseases with similar clinical presentations. Historically classified into three types, Types A and B are now considered to be part of the same spectrum of a single disease. Those with Type A generally do not survive beyond early childhood, while those with Type B tend not to experience neurological problems. Those with Type C may have dementia-like cognitive difficulties.

Because of their rarity, the Niemann-Pick diseases are often referred to as 'orphan diseases'. The term 'orphan' refers to diseases that affect only small numbers of individuals. In Europe, the definition of an orphan disease is one affecting less than 5 people in 10,000. Because of their rarity, orphan diseases do not tend to attract a great deal of public attention, research or funding.

Although extremely rare (there are around 90 diagnosed cases in the UK), the effects of NPD are devastating, with many children not surviving into adolescence. The Niemann-Pick Disease Group (UK) provides a source of support and information for those families who are affected by NPD. For further information, please visit [www.niemann-pick.org.uk](http://www.niemann-pick.org.uk).

## Don't miss our second **self-directed support conference**

Following the success of our first conference on self-directed support in 2011, plans are now well underway for the second national conference and exhibition, which will take place in Glasgow on 23 September.

This year's Self-Directed Support and Dementia in Scotland conference will explore the theme 'Getting Creative!'. It will focus on the potential of the new Social Care (Self-directed Support) (Scotland) Act 2013 to improve the quality of life for people with dementia at every stage on the journey of dementia.

Self-directed support (SDS) is a powerful way of helping people with dementia to remain active



citizens for as long as possible. The conference will look at the principles behind SDS along with how to access it and the benefits it offers. It will also explore innovative and creative ways of making SDS as effective as possible.

The keynote speaker will be Michael Matheson MSP, Minister for Public Health, who will talk about the future direction of care services for people with dementia in Scotland. As well as presentations, there will be an exhibition and a choice of practical workshops.

The conference will take place at the Thistle Hotel, Cambridge Street, Glasgow, G2 3HN on 23 September from 10:00–16:30. The registration fee is £100 per person. Discounts are available for multiple bookings and there are free places available for people with dementia and their families.

To book your place or for more information, please contact Kirsty Wilson on 0141 410 1068 or visit [www.alzscot.org/SDS2013](http://www.alzscot.org/SDS2013).

## Shaping the future of **self-directed support**

Alzheimer Scotland recently submitted a response to a Scottish Government consultation on new regulations and guidance relating to self-directed support (SDS). The consultation closed on 10 July and feedback from it will be incorporated into the draft regulations and guidance, then presented to Parliament in the autumn. Once finalised, the new guidance will accompany the Social Care (Self-directed Support) (Scotland) Act 2013.

To ensure the voices of people with dementia, their families and carers were heard, we organised regional focus groups in four locations during May and June, as well as with the Scottish Dementia Working Group. Others who couldn't attend a focus group submitted individual responses.

Alzheimer Scotland also worked in partnership with Scottish Care to organise a collaborative event which brought together those who use services and carers with representatives of service-providing organisations. This took place in Dunfermline on 6 June with more than 100 people and over a dozen organisations participating.

Kate Fearnley, Deputy Chief Executive of Alzheimer Scotland, chaired the event, saying: "Self-directed support presents an

opportunity to fundamentally change the way that people who need services are supported, empowering them to shape and manage their own support in the way that best suits them. I think I can safely say that everyone who participated in this consultation event warmly welcomes the new legislation, and that the 100 or so people in the hall were all there in a spirit of genuine positivity, seeking to contribute their considered thoughts about the guidance and regulations. The report we have submitted describes their joint deliberations, and I believe makes a positive contribution to ensuring that the guidance and regulations on SDS will be as effective and helpful as possible."

You can download a copy of the report by visiting [www.alzscot.org/SDSreport](http://www.alzscot.org/SDSreport)

# Forget-Me-Not-Ball promises an evening of luxury

Join us in the sumptuous surroundings of the George Hotel, Edinburgh for our very first Forget-Me-Not Ball on Saturday 19 October. This spectacular black tie event promises to be a night to remember. Your host for the evening will be Austin Lafferty, Past President of The Law Society of Scotland, and the ball will take place in the George Hotel's luxurious King's Room.

Enjoy a sparkling champagne reception accompanied by harpist Julia Somerville, followed by a delicious three-course dinner with

table entertainers. Other highlights include a full cabaret, a charity raffle, a spectacular auction and dancing till 1 am to 'Big Night Out'.

But that's not all. During the evening two lucky guests will win a holiday for two at a luxurious 5 star hotel in Malta including flights courtesy of the Westin Dragonara Resort and Spa, St Julian's, Malta.

Demand for tickets is sure to be high so to avoid disappointment please book now. Tables of ten are only £700. To book call the ticket hotline 0131 243 1453.



The King's Room at the George Hotel

## Join us for our 2013 Sports Dinner in November



Alzheimer Scotland's 2013 Sports Dinner will take place in November (date and venue to be confirmed). Among the speakers will be professional snooker referee, Hugh Brown – a very amusing after dinner speaker. The dinner will be hosted by Ian Adie, well-known Glasgow businessman and Champion's League storyteller.

Tickets cost £50 each, which includes a drinks reception

and fabulous three course dinner. During the night there will be charity raffles and auctions with magnificent prizes, including:

- a week in a beautiful penthouse in Tavira in Portugal
- a long weekend in a cottage in Tayport, near St Andrews, with a round of golf thrown in
- an original Paine Proffitt painting of a footballer of your choice

- the opportunity to shadow a Sun sports reporter at a football press conference
- the chance to sit in on the Des & Jennie show at Capital FM.

We are also offering the opportunity to 'purchase' a former Football Legend to host your table for the evening!

This promises to be an evening full of fun, laughter and stories, with lots of chances to win great prizes. The dinner will raise money for the Football Memories Project which provides reminiscence-based therapy for people with dementia who have an interest in football. Over 50 groups have been set up throughout Scotland to date, and the funding will support existing and new groups.

For further information please contact Ellenor Ferguson at [eferguson@alzscot.org](mailto:eferguson@alzscot.org); 07811 045600 or Sheila Connell at [sconnell@alzscot.org](mailto:sconnell@alzscot.org); 0141 410 1062.

## Will you 'Drop for Dementia'?

You're standing on the edge! Your heart is pounding! It's a long way down! Will you take that leap of faith and 'Drop for Dementia' on Sunday 22 September 2013? Be one of the first to abseil 150 feet from the stunning Penielheugh Monument on the hilltop just outside Jedburgh in the Scottish Borders.

The Penielheugh Monument was built to commemorate Wellington's victory at the Battle of Waterloo and there are wonderful views of the Scottish Borders from the top.

No previous experience is needed to take part, and our team of highly skilled instructors will ensure you are equipped with all you need to make your abseil safe, exciting and enjoyable.

We ask for a registration fee of £20 and a pledge from you to raise a minimum of £125 for Alzheimer Scotland. This will guarantee you a place. For more information please call 0131 243 1453 or enter online at [www.alzscot.org/bordersabseil](http://www.alzscot.org/bordersabseil)



## Arthur's Seat pyjama fundraiser



Jaya, Natasha and Yesi

Three 11 year old girls took on the challenge of their young lives recently when they climbed and ran the 251 metres to the top of Arthur's Seat in Edinburgh an incredible 12 times over two days. Not only that but they did it in their pyjamas! Schoolgirls Yesi Wood, Natasha Sharma and

Jaya Robinson raised an amazing £803 for Alzheimer Scotland. The intrepid trio came to our HQ to hand in the money, where Yesi, the youngest of the three girls, explained why they had taken on the feat. "My Grandad has dementia and I decided to persuade some of my friends to help me raise funds for the charity who helped him a lot and we came up with this idea. We decided to do it in our pyjamas just for fun. Even the people we met when climbing the hill were giving us money. It was great fun." We are all incredibly impressed with what Natahsa, Jaya and Yesi have accomplished and would like to thank them again for their fabulous fundraising achievement.

## Award for Aberdeenshire primary pupils

Pupils from Hill of Banchory Primary School recently received a Social Enterprise in Education Award from John Swinney MSP. Each month, a group of people with dementia, carers and staff meet at the school where they enjoy the company of the children and have an afternoon of fun. Different year groups take turns to share their talents, with musical entertainment proving a popular option. Song sheets enable everyone to join in with familiar tunes, and afterwards the children and adults sit together and chat whilst enjoying afternoon tea together. The afternoon is rounded off by the school's Cooking Club selling old fashioned sweets



to their guests as part of their business enterprise. The children's awareness of Alzheimer Scotland has also led to fund-raising activities. The Social Enterprise Academy praised the partnership for helping raise awareness of dementia and enabling young and older members of the community to connect.

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