



Dementia in Scotland



1 year post diagnostic support

GUARANTEED

Exclusive Nicola Sturgeon explains this world first commitment



We are the Champions! 100 new Dementia Champions for Scotland



Post-diagnostic support – a personal account



Our Dementia Nurse Consultant in Lanarkshire hits the ground running

One year post-diagnostic support - guaranteed

A world first for dementia

Last year, we asked the Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy, Nicola Sturgeon MSP, to guarantee that people receiving a diagnosis of dementia would be offered one year of post-diagnostic support from a named and well trained person. It was a momentous decision when she said yes.

Here, the Deputy First Minister explains to Dementia in Scotland why she agreed to give this ground breaking commitment.



What is the Deputy First Minister's personal commitment to the one year Post-Diagnostic Support guarantee?

As we moved into this second term I made dementia and older people's services my personal policy priorities. These issues are, quite rightly, staying at the forefront of the social and political agenda. We published Scotland's National Dementia Strategy in 2010, and one of its two key improvement areas is post-diagnostic support. Last December I told the National Dementia Forum that I was putting in place, for the first time, a national commitment to reflect the personal priority I attach to making improvements in this key area and providing a

guaranteed minimum of one year post-diagnostic support.

For me, it is vital that I have a specific focus on this area of care – because I know that getting the right support in place at this stage of the illness can greatly help improve the quality of care throughout the journey of the illness. I know that Alzheimer Scotland share my conviction and my determination to deliver this commitment.

This guarantee is (as far as we can tell) a world first - how will the post-diagnostic guarantee of a minimum of a year's support enable people with dementia, their carers and families to live well with the illness?

While there are good local examples of post-diagnostic services, provision is currently inconsistent. Underpinning this commitment will be a link worker, assigned to work with the person and their family and carers in co-ordinating support and building a person-centred support plan, based on Alzheimer Scotland's "5-Pillar" model. Providing this support will be key to supporting people in adjusting to a diagnosis and its likely impact - both emotionally and practically; and in helping them plan for the future and navigate through the key issues and supports available. We want the commitment to help people with dementia live well in their home and in their community for as long as possible. The person-centred plan will help empower and inform people in being at the centre of their care as the illness progresses and will be a key resource to be accessed by professionals.

As part of this commitment, through this year we are supporting test sites in Glasgow City, South Ayrshire, Argyll and Bute and East Renfrewshire – they will provide us with more information on the workforce and resource implications for local services of delivering the strategy.

What does the Scottish Government mean by 'world class dementia support' and how are we implementing that across Scotland?

Providing world-class dementia support means, among other things, working with Alzheimer Scotland and others in sustaining and building on our impressive achievements in early identification and diagnosis; improving post-diagnostic services; and treating people with dementia with dignity and respect at all times and in all care settings, including of course acute hospital settings. The Dementia Strategy is designed to make real and measurable improvements in these and other areas over its initial 3-year period. But building world class dementia services for the years to come, with our ageing population, also means working within the Dementia Strategy to influence wider action on transforming older people's services.

What are the benefits of having a Scotland-focused approach to dementia (incorporating Scotland's demographic challenges both now and in 25-30 years' time)?

We are all well aware of the demographic challenges we are facing up to and planning for right now. While there are approximately 82,000 people in Scotland with dementia today, as our population ages that number is projected to double over the next 25 years. That's presented us with a significant challenge. It's part of our wider challenge on older people's services and one we're addressing with our partners across the statutory and third sectors by providing a Change Fund to help local partnerships build stronger community and family-based and person-centred services - and in doing so lessen the pressure and costs associated with long-term care. We've also been supporting local partnerships in Midlothian, North Lanarkshire and Perth and

Kinross in demonstrating the benefits of the local whole-system re-design of dementia services.

What are the benefits for the Scottish Government of working with organisations such as Alzheimer Scotland in implementing the Dementia Strategy?

Development of the Dementia Strategy included the close involvement of Alzheimer Scotland and the Scottish Dementia Working Group, both of whom endorsed our approach. It has been vital to me that, in implementing the strategy, they have both been at the heart of the large programme of work, providing expert advice and input on the services to which people are entitled, and influencing the implementation of the various strands of the strategy. I also look forward to hearing the views of, and working with, your new Carers' Group.

What about implementation of the Standards of Care for Dementia in Scotland?

There's been a huge demand for the standards from services across all sectors and I know that they're being used to help improve local services and identify where the gaps in provision are. People with dementia and their families are also using the standards to get the services to which they're entitled. Scrutiny bodies will also use the standards when inspecting services. We're going to consult on a review of the National Care Standards - and part of that will include ensuring that they are aligned with the dementia standards.

How important is the implementation of Promoting Excellence?

I'm clear that taking this national approach, for the first time, to developing and up-skilling the dementia workforce across health and social services is key to helping services meet the dementia standards and to improving

people's experience of services. Indeed, it's what people told us was vitally important as we developed the Dementia Strategy. As part of this programme of work, I was delighted to see the launch of the *Informed About Dementia* DVD in February and the first 100 Dementia Champions graduate in March.

We also continue our joint endeavour with Alzheimer Scotland to appoint a Dementia Nurse Consultant to every NHS Board in Scotland this year. These posts will complement the work of the Dementia Champions. The Nurse Consultants - some of whom are already in post - will play a key expert role in supporting, facilitating and advising on service improvement within their Board.

What about the NHS Healthcare Improvement Scotland inspections of hospitals?

Improving services in acute hospitals is the second key improvement area in the strategy. Earlier this year I asked the Chief Nursing Officer to lead a programme of work to assure me on the quality of care in hospitals for all of our older people. As part of this process, in February, Healthcare Improvement Scotland (HIS) began a programme of inspections to run through this year into the standard of care of older people in acute general hospitals, including against the dementia standards. I expect HIS to publish their first report in April.

I'm delighted to contribute to this issue and I look forward to continuing to work with Alzheimer Scotland on the new post-diagnostic commitment and the rest of the dementia strategy.

Alzheimer Scotland welcomes the Deputy First Minister's announcement



Alzheimer Scotland has campaigned for improvements in early diagnosis and post-diagnostic support for many years and we were pleased that improving post-diagnostic support was one of the key priority areas in the National Dementia Strategy. However, as the strategy began to be implemented we were disappointed in the pace and lack of consistent improvement in delivering post-diagnostic support across Scotland.

Our serious concerns led us to argue for the introduction of a minimum guarantee and to put forward the “Five Pillars” post-diagnostic support model outlined in the following pages.

We are delighted that the Cabinet Secretary for Health, Wellbeing and Cities Strategy, Nicola Sturgeon, listened to our concerns and has agreed to make a national commitment, guaranteeing that

every person diagnosed with dementia and their family will receive a minimum of one year’s post-diagnostic support from a named and well trained person.

We believe that this is a world first and a world-leading commitment and we commend the Scottish Government for making it. This is a significant milestone in dementia care and we expect it to be a life changing commitment for the 7,000 people in Scotland diagnosed with dementia each year, and for their families.

The challenge now is to deliver it. This will require a major shift in both practice and culture. However few people do not support this approach and I am certain we will have the support of all professional groups to make this a success.

Henry Simmons
Chief Executive, Alzheimer Scotland



Dementia Champions from Shetland, with their Director of Nursing (right)



Dementia Champions from NHS Lanarkshire

Coming to terms with **dementia**



“She said: ‘You’ve got vascular dementia. Come back and see me in six months.’ Then she sent me on my way.”

Henry Rankin tells Dementia in Scotland how post-diagnostic support helped him and his family come to terms with vascular dementia.

“It was dreadful. Absolutely dreadful. There’s no other way to describe it. She said ‘You’ve got vascular dementia. Come back and see me in six months.’ Then she sent me on my way. No more information, no-one to speak to. I didn’t even know what vascular dementia was. I thought it was all over, that I had six months left to live. I walked out to the street and burst into tears.”

Henry Rankin is unequivocal about the manner in which he was given his diagnosis of vascular dementia at the age of 58. After months of trying to find out the cause of his memory problems and receiving little in the way of answers, it seemed like the

final straw. He and his family were forced to look online for information about his illness, but could never discover what they really wanted to know: how to cope with dementia and what Henry’s future was, if any.

However, Henry was fortunate enough to live in East Renfrewshire, where Alzheimer Scotland’s *Facing Dementia Together* project is based. *Facing Dementia Together* provides information and support to people recently diagnosed with early stage dementia, their families and friends. It also aims to help people take control of the supports they need throughout the illness, as well as putting them in touch with other people in the same situation.

“I can’t praise Tracy [Gilmour, Manager of the project] highly enough,” says Henry. “She put me at my ease straight away. She reassured me, gave me my confidence back. The way I’d got my diagnosis had knocked the wind right out of my sails, but she got me back on track. She spoke to my family too, gave them lots of information and advice. Best thing

was; she was always there. We could speak to her at any time.”

Tracy was able to put Henry and his family in touch with the various people, groups, public sector agencies and other organisations required to help the Rankins plan for future legal, financial and care needs, as well as assisting them with the form-filling involved.

Tracy also put Henry into contact with the Scottish Dementia Working Group. He (with several other SDWG members) recently attended the Alzheimer’s Disease International annual conference in London and was asked to speak during one of the discussions – an experience he thoroughly enjoyed.

As Henry points out, “If someone is told they have cancer, they’re pointed toward people that can help them. That didn’t happen to me. They need to get diagnosis and post-diagnostic support right for people with dementia and their families. I’m glad the government’s made a commitment to making that happen. It’s brilliant news... and not before time!”

The Facing Dementia Together project made a film at one of their café sessions where people with dementia and their families, including the Rankin family, talk about the difference the project has made to their lives. You can watch the film at:

<http://dementiascotland.org/services/east-renfrewshire/facing-dementia-together/>

As Tracy Gilmour, Post-Diagnostic Practice Manager, says: “Normally what would have happened in the past would be that people would get their diagnosis but supports really wouldn’t come into play until they were maybe struggling or they’d hit a crisis point.

“If we can help people earlier on and provide them with information and support and they can start to think about what kind of support they might need in the future, then that hopefully will keep people well for longer, promote independence and help them feel more in control.”

Getting post-diagnostic support right for people with dementia – **the Five Pillars model**

Improved post-diagnostic information and support is recognised in Scotland's National Dementia Strategy as one of two key service delivery areas in which immediate change is required. There is clear evidence that high quality post diagnostic support, provided over an extended period, is essential in order to equip people with dementia and their families and carers with the tools, connections, resources and plans they need to live as well as possible with dementia and prepare for the future. The

positive effect which this kind of support can have on people's lives has been demonstrated in the post-diagnostic support pilot funded by the Scottish Government and delivered by Alzheimer Scotland, and international evidence shows the long term impact in reducing and delaying the need for care services.

There are five key pillars which are recognised as essential to supporting people after their diagnosis, outlined in the diagram below.



One year guarantee

The purpose of the guarantee we sought from the Cabinet Secretary is to provide the security, for a minimum of one year, of a named person who has the flexibility to work alongside the person, their partner and family and ensure that over that 12 month period each person is given help and support to work through

the five pillars. By the end of the year it is expected that some individuals might require ongoing professional support; however the purpose of the post-diagnostic support is to enable the individual and their family to develop a robust personal plan that utilises all their own natural supports, that maintains newly developed peer support mechanisms alongside existing and new community

connections and that will support each person to live well and independently with dementia for as long as possible.

Personalised, flexible support

It is imperative that post diagnostic support is personalised and flexible, and delivered proactively and sensitively over the course of a year by a skilled and well-

trained person, who can develop a supportive relationship with the individual and their partner and family. There is no preferred systematic order in delivering this support; each person will need a unique approach and professionals will need to identify when that person and their family are ready to engage in each area. Some people will need time without too much support, to absorb their diagnosis of dementia; others might need to begin planning their future right away, while others might need help to maintain their community connections and not withdraw from aspects of everyday life that are keeping them active and engaged.

How the model can work – the five pillars

The five pillars in our model highlight key areas of activity. Various techniques and approaches can be used to deliver a given pillar, but it is essential that the full range is offered to each person. Some examples of what this will mean in practice and suggested techniques are outlined below.

1. Help to understand the illness and manage its symptoms

– supporting people with dementia and their partners and families to come to terms with dementia and learn to self manage their condition. This pillar must involve the person's partner, family and natural support network. It will mean breaking away from the traditional patient-professional model, to a more patient-family/network model of living with dementia. Approaches such as Family Group Conferencing and other methods of family engagement will inform this work.

2. Support to stay connected to their community

- working closely with people to maintain and build on their existing social networks, to enhance their quality of life and maximise the natural support they receive from those around them, helping to avoid isolation and reducing future reliance on care

services. This will require a shift away from traditional health and social care boundaries. The named worker will need to work with the person to enable risk, plan purposeful community activity and connection, and to engage with community development partners and organisations to help people with dementia continue to use and be fully included in mainstream community activity.

3. Peer support from other people with dementia and their families and carers

– this is highly effective in helping people come to terms with the illness and find coping strategies, and in maintaining their wellbeing and resilience. A good example of peer support is the dementia cafés run by Alzheimer Scotland and others. These allow people with dementia and their families and carers to attend together, in a relaxed informal atmosphere where they can get information from professionals but, most importantly, have the opportunity to meet other people facing similar challenges. Feedback from people using the cafés in Alzheimer Scotland's post-diagnostic pilot shows how much they value this. They said that the cafés helped in all kinds of ways, helping them see how you can live positively with dementia and helping families to think about balancing independence with risk. Having a forum for open discussion of these issues helped everyone to cope better, and enabled greater independence and reduced frustration all round.

4. Help to plan for their future decision-making

– support to set up powers of attorney and other statements of their wishes while they are able to make their own choices about the future. This will include dealing with very sensitive issues in a skilled and informed manner. It also gives a focus to issues such as advance directives and Adults with Incapacity issues and will also ensure that each person has a good understanding of Self Directed Support.

5. Support to plan the shape of their future care from their own perspective - together with those around them, developing a personal plan with their choices, hopes and aspirations, which can guide professionals. Person-centred planning offers a variety of tools and techniques to assist this process. This approach has been used extensively in other fields of practice, but not previously with people with dementia. The Alzheimer Scotland pilot showed that existing tools can be successfully adapted to help people with dementia to think creatively about the support they might require and about how the people around them can offer support. The basis of person-centred planning is that the emphasis shifts away from professional inputs and expectations. Instead, it builds on the hopes and expectations of the person and their family and uses techniques to place these hopes and personal outcomes at the centre of practice. It goes beyond person-centred approaches and converts the person's hopes into a live plan, with a series of goals, steps and outcomes that those involved in that person's life will help to deliver. In this scenario, professionals are equal contributors alongside family and friends and the focus is always on the person. The person owns the plan and it can be used to lead future interventions and as a method of planning transitions.

Other methods exist to develop and work towards a more personal outcomes-based approach, such as the use of Talking Points. The named person should be equipped to use and have access to a range of interventions and planning tools that he/she can offer to each person. The essential focus must be on supporting personal choice, personal strengths and achieving individual outcomes. How this is achieved will be varied and highly personalised.

Henry Simmons
Chief Executive
Alzheimer Scotland

Definitely not the missing link!

Alzheimer Scotland has, for several years, employed Link Workers in some areas to support people with dementia and their partners and families in the period immediately after diagnosis and beyond. Thanks to new funding streams, including the Reshaping Care for Older People Change Fund, we hope to offer this key support in many more parts of Scotland and expect to be employing more new post-diagnostic staff over the next few months (see page 19).

Our Dementia Link Workers, in conjunction with colleagues from other disciplines and agencies, are there to support individuals with dementia, their families and friends, after diagnosis, providing ongoing support and information, and connecting people to peer support or appropriate services. They support people within their own communities and help them develop coping strategies to live as well as possible with their diagnosis.

To explain more about what they do, we asked two Link Workers to describe their role.



Rosemary McCrae has been a Memory Clinic Link Worker for two years. Employed by Alzheimer Scotland, her post is part funded by the NHS and she is based within the Community Mental Health Team which covers Annandale and Eskdale in Dumfries and Galloway. A qualified social worker and experienced lecturer, Rosemary now works four days a week supporting people who have recently received a diagnosis of dementia.

"I currently have a case load of 28 people with dementia and 30 carers. Following people's diagnosis, I go out and provide education, advice and support to those people and their carers, usually within a 3 week window of them getting their diagnosis. This involves, for example, providing Alzheimer Scotland publications, discussing Power of Attorney and the reasons people should have this, Attendance Allowance and why people may be entitled to this (I work closely with the council benefits department and will put all of my referrals through them)."

"I find that my support visits are not just for the people who have received a diagnosis, but equally important is the support I provide to carers. Emotional support to everyone involved probably takes up most of my time on the first few visits; however, I slowly see people's confidence returning as they find new coping strategies we have identified and this in turn often reduces the carer stress people are experiencing."

"I also work with the Dementia Advisor in my area and we run two 'Forget me Not' support lunch groups which allow people and their carers to socialise with people in a similar situation to themselves as well as allowing them to gain some peer support, both for the people with the diagnosis and their carers. I also find the monthly lunch groups allow people to keep in touch with me on a light touch support basis."

"If required, I can link up and network with other relevant agencies such as Social Services, Occupational Therapy, day care facilities, etc. I always ensure people have any required supports in place before I discharge them."

Rosemary works as part of a multi-disciplinary team which includes

Community Mental Health Nurses, an Occupational Therapist, a Social Worker specialising in Mental Health, and a Support Worker. She also attends Memory Clinics with the Consultant/GP and undertakes further assessments if needed. She also offers support to partners and family members at the clinic. "Because I meet them at their point of diagnosis, I am then a familiar face when I go out to start my support visits around 3 weeks after their initial appointment."

Rosemary says: "I feel the Memory Clinic Link Worker posts provide valuable support at a very appropriate time to people. Many carers have told me that they wish someone like myself had been available when their own mother/father received a diagnosis years ago as they were left to 'muddle away' as best they could."

Helen McKenzie is a more recent recruit to Alzheimer Scotland, joining us two months ago as a Link Worker based in Motherwell.

Having taken early retirement from being a GP, Helen now spends her time contacting and visiting newly diagnosed clients and making follow up visits or phone calls. "I liaise with various agencies depending on people's needs. I also attend local support groups and Dementia Cafes and I hope to attend multidisciplinary meetings as I build up professional relationships."

Like Rosemary, Helen does not have a fixed time period for working with people and their families – it all comes down to each person's needs. "If people don't want my input or they are now being assisted by our Support Team, then I will step out of the picture. I can always re-establish contact if I'm needed."

More Alzheimer Scotland Dementia Nurses Consultants come on board

Alzheimer Scotland Dementia Nurses work with NHS colleagues to increase staff understanding of dementia and improve standards of care. Our Dementia Nurse programme began in 2006, with posts created in NHS Greater Glasgow and Clyde, NHS Borders, NHS Lothian and NHS Ayrshire & Arran over the next four years. In 2010, we launched our Dementia Nurse appeal, spearheaded by the Duchess of Hamilton, which aimed to place an Alzheimer Scotland Dementia Nurse in every NHS board in Scotland. Thanks to the generosity of thousands of donors and joint funding from the Scottish Government, 10 new Dementia Nurse Consultant or Specialist Nurse posts are now in development across Scotland.

NHS Lanarkshire was the fifth health board to join our Dementia Nurse programme, with the appointment of Maureen Taggart as Alzheimer Scotland Dementia Nurse Consultant in late 2011.



"I've been working in NHS services for Older Adults and Mental Health for 35 years," says Maureen, who has been in a wide variety of roles, including training, Service Development Manager for Mental Health and NHS Lanarkshire Lead for Old Age Psychiatry. Her passion for the post is clear, "I love being

an Alzheimer Scotland Dementia Nurse; it feels like I've found my perfect niche."

Maureen advises Directors and Executive Directors of Older Adults, Mental Health and Nursing in the board, providing valuable information on dementia in both acute and primary healthcare settings. She also works closely with hospital staff to employ the practical changes outlined in the *Promoting Excellence* training framework. She greatly welcomes the most recent instalment, the *Informed about Dementia* training resource (jointly produced by NHS Education Scotland and the Scottish Social Service Council - see page 13). She says, "I see it [*Informed about Dementia*] as not just being something NHS Lanarkshire should aspire to, but a standard that all of our staff can and will achieve."

There have already been several successes. One is her work to apply the Butterfly Scheme – a model devised by a carer called Barbara Hodgkinson (whose mother had dementia) to improve patient safety and wellbeing in hospitals. This is based on the acronym REACH:

- Remind – the patient what has led to this moment
- Explain – what is about to happen
- Arrange – helpful clues and important items to be visible, consistent and accessible
- Check – hydration, hygiene, eating patterns, etc
- History - of any kind must always be verified from the records, staff or carer; all instructions, including taking medicines, must always be backed up.

In addition, through the Practice Development Centre and in

conjunction with the University of the West of Scotland, 64 NHS Lanarkshire Charge Nurses have undergone training in dementia, delirium and depression in older people. Maureen is also working to reduce the inappropriate prescribing of psychoactive medication by monitoring the use of such treatment on a ward by ward basis; this allows her to step in with information (and training, where required) if a ward's prescribing rates are too high. She has also been keen to encourage the use of e-learning for staff in acute wards and accident & emergency units.

Despite these early achievements, Maureen feels that there is a "huge amount yet to do" in NHS Lanarkshire. While most staff want to provide better care for people with dementia, many have received little training on the illness. For those who were originally trained 20, 30 (or even more) years ago, what they were taught about dementia is likely to be out of date. She has also been working to create dementia-friendly ward environments, but this has been easier in some hospitals than others.

Bringing everyone up to speed with the standards of knowledge and understanding outlined in *Promoting Excellence* will take time. It will also take enthusiasm and commitment – which Maureen Taggart has in abundance.

Kirsty Jardine

Awareness Manager, Alzheimer Scotland

We are delighted that NHS Education for Scotland will provide a one-year leadership training programme for our new and existing Dementia Nurse Consultants and Specialists.

100 new champions for dementia



Scotland's new Dementia Champions at their graduation

Scotland has 100 new dementia champions within our acute health care services. The champions were congratulated by Nicola Sturgeon, the Deputy First Minister and Cabinet Secretary for Health and Wellbeing at a ceremony held in 'our Dynamic Earth' on 14 March to celebrate their graduation.

The Dementia Champion programme was commissioned by NHS Education for Scotland and the Scottish Social Services Council. In partnership with the University of West of Scotland (UWS), Alzheimer Scotland designed and delivered the programme to prepare these acute service staff as dementia champions and leaders of change. UWS has the largest

School of Nursing, Health and Midwifery in Scotland with over 4,000 students studying across 4 campuses and online.

Staff completing the champion programme will work in partnership with families and colleagues towards ensuring people with dementia have a much improved experience in our Scottish hospitals and wherever possible, return home in a planned and supported manner. The new champions will promote understanding amongst their own teams of the impact of the acute care environment upon someone with dementia and help staff to anticipate and respond sensitively. They will play an important role in enhancing

the recognition, assessment and identification of dementia in addition to promoting excellence in the care and support provided to those who already have a diagnosis.

The dementia champion programme is a key aspect of the implementation of Scotland's National Dementia Strategy. Participating staff came from a variety of health disciplines and sites across Scotland and important features of the programme have been sharing practice and developing a commitment to bringing about a more dementia friendly environment, care and culture within our hospitals.

The programme was designed using a blended learning approach with the champions engaging with online resources, attending face-to-face interactive training sessions and experiencing a short placement in a community setting. Access to resources was enabled via a virtual learning environment which also served as a communication hub between the champions themselves and with their lecturers. Each champion had their own personal tutor in recognition of the challenging nature of both the course and implementing change within established systems and cultures.

Assignments undertaken by the champions facilitated personal and organisational reflection on practice and a focus on action was enabled through the use of a specifically designed self-assessment tool. Evaluation suggests some of the most powerful and motivating experiences were the involvement of family carers in the face-to-face sessions and the community placement, which enlightened staff about the daily lives and the potential of people with dementia when they are not acutely ill.

Experiences on the programme have reinforced the importance of having a more personalised approach and working with the person with dementia, their family, friends and communities in meaningful partnership to realise better health outcomes for individuals. Even before reaching the end of the programme the participants had made significant changes to improve experiences for people with dementia within their own hospitals including the introduction of information and signage, use of life story material, dementia signifier systems, developing educational resources for staff and initiatives to involve relatives and volunteers.

The dementia champions form part of an important and increasing network of health staff with a specific remit to protect and promote the rights of people with dementia and their families to the highest quality of personalised support. They will work closely with the Alzheimer Scotland Dementia Nurse Consultants within each NHS Board and with the Allied Health Professional Consultants to exert influence over local practice and wider strategic policies. These initiatives are the result of co-operative and committed partnerships between Alzheimer Scotland, the Scottish Government, Health Boards and Higher Education.

We are delighted to be afforded the opportunity to continue our partnership with UWS as we prepare to deliver a further programme to another 200 dementia champions in the year ahead. This time the training will include social care staff who can assist in preventing hospitalisation, influence an enhanced experience in hospital when this is essential and support earlier well-planned discharge.

We believe these initiatives provide a positive example of what can be achieved when educational and practice expertise are brought together in a spirit of co-operation and commitment to enhancing the lives and experiences of people with dementia and their families.

We would like to add our congratulations to the graduating champions who have worked so hard over the last 6 months and we look forward to continuing to work with you and your colleagues in the future.



Barbara Sharp
Practice Development Manager,
Alzheimer Scotland

Is the National Dementia Strategy working for you?

The National Dementia Strategy should be having a positive impact through:

- improved support following diagnosis
- improved care and treatment in general hospitals
- improved quality of care through new dementia care standards and training
- better responses to behaviours that challenge
- better integration of health and social care services.

Alzheimer Scotland would like to hear about your experience to help find out what impact the National Dementia Strategy is having across Scotland. We are interested in both positive and negative experiences. Any information you provide will be reported anonymously to the Scottish Government.

Tell us your story

You can add your story direct to the Alzheimer Scotland website or download the form from this web page:

<http://dementiascotland.org/dementia-strategy/local-dementia-strategy-feedback/>

Alternatively, you can write to:
Lindsay Kinnaird,
Alzheimer Scotland,
22 Drumsheugh Gardens,
Edinburgh EH3 7RN;
email: lkinnaird@alzscot.org

Guide to Dementia Standards published

Alzheimer Scotland has published a guide to the Standards of Care for Dementia in Scotland. The new guide is aimed at people with dementia and their family members, partners and friends.

It explains:

- what your rights are
- the quality of care, support and treatment you or the person you care for should receive to stay well, safe and listened to
- how you can use the standards to ensure the services you receive meet the standards
- what you can do if you are not happy with the standard of care, support and treatment provided.

A free copy of the guide may be ordered from Lucy Glenny, Administrator, Alzheimer Scotland. Tel: 0131 243 1453; email: lglenney@alzscot.org, or download from our website www.alzscot.org

New Deputy Director-Policy



We are delighted to announce that Jim Pearson has been appointed as Deputy Director – Policy with Alzheimer Scotland. Jim will be familiar to many of you as our former Welfare Rights Manager, a post he has held since January 2000.

Manifesto for May 2012

Local Government Election Thursday 3 May 2012

Now that we have achieved the right level of focus on post-diagnostic support, it is time to return our main focus to those people already living with dementia in their own home, residential or nursing care. The Local Government Elections in May will be a crucial campaign for us and we will be writing to every candidate asking them to sign up to a pledge agreeing to make dementia a local priority for them, if elected. In this economic climate, we must do all that we can to ensure that the dementia specific services commissioned by local authorities and delivered by the voluntary, independent and statutory sectors are all protected and not consumed into generic services in an attempt to make savings.

We will launch this campaign in April and more details will be available on our website at www.alzscot.org; so if any candidate is looking for your support, please tell them about our campaign and ask them to sign up.

New sources of information

Informed about Dementia DVD launched

NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) have produced an educational resource for the entire health and social services workforce in Scotland. Entitled *Informed about Dementia: improving practice*, the DVD will help ensure that all health and social services staff understand more about dementia and can think differently about the people with dementia that they might work with, either directly or indirectly.

Henry Simmons, Chief Executive of Alzheimer Scotland and Chair of the NES/SSSC Programme Board, said: "Everyone working in health and social care, from receptionist to consultant, should watch and learn from this DVD: it will help to ensure that people with dementia, their



Front row – Geoff Huggins (Head of Mental Health, Scottish Government), Henry Simmons (Chief Executive, Alzheimer Scotland), Dr Lindsay Burley (Chair, NHS Education for Scotland). Back row – Garry Coutts (Convener, Scottish Social Services Council), Agnes Houston (Chair, Scottish Dementia Working Group), Ross Campbell (SDWG), David Batchelor (Vice Chair, SDWG)

families and carers are treated with dignity and respect. We believe no one should go through dementia on their own; this DVD can help all staff to play their part".

A clip from the DVD can be viewed here www.knowledge.scot.nhs.uk/home/portals-and-topics/dementia-promoting-excellence.aspx

Living well with dementia DVD

This DVD has been produced by NHS Health Scotland in partnership with Alzheimer Scotland and the Scottish Dementia Working Group (SDWG). It is designed for individuals and their families who have just been given a diagnosis of dementia. The DVD is based on footage from the SDWG film *Through our eyes*, with new footage adding carers' voices and signposting to services for support and information.

The DVD can be viewed in English (with or without subtitles), British Sign Language, Polish, Chinese and Urdu.

People with dementia and their families and supporters can get a free copy of the DVD from the Dementia Helpline on 0808 808 3000. Professionals should order

copies via their local NHS health promotion department – contact details also available from the Dementia Helpline.

Essential conversations: talking about death and dying

Talking about dying is not an easy topic; it's not something that fits neatly into bullet points or actionable processes. It is an intrinsically personal experience for everyone – possibly even more so when it involves dementia.

We have developed *Essential conversations*, a DVD that acts as an 'emotional resource' for care staff, helping them to enhance their skills and confidence in supporting people with dementia and their families.

For further information, visit www.essentialconversations.org.uk or for a copy of the DVD contact

Jenny Henderson at jhenderson@alzscot.org; tel: 01387 261303.

Dementia Advisor Network grows to 29

We are delighted to welcome a further six new Dementia Advisors to Alzheimer Scotland. **Anne Heinrich** is based in Elgin; **Susan Chandler** joins us in Inverclyde where she works out of our new Dementia Resource Centre in Greenock; **Ann Williamson** is our most remotely based Dementia Advisor, in Shetland; **Fiona Dendy** covers North Highland from a base in Invergordon; and **Jane Maskelyne** joins our team in Fife where she will work out of our Dementia Resource Centre in Kirkcaldy.

We are sorry to say goodbye to Sheila MacIver who retires from her post in South Highland at the end of March but welcome **Geraldine Ditta** who is taking over from Sheila.

Crafty challenges

Why not revive your crafting skills and help Alzheimer Scotland with one (or both!) of our challenges for nimble fingers.

Hampden Quilt Challenge

Those of you who attended our 2010 AGM will have seen some beautiful examples of quilts on display, courtesy of Dumfriesshire-based Ann Hill, Alzheimer Scotland's quilter in residence. During the past few years, Ann has been working with people with dementia, their families and staff at various care homes, hospitals and groups. This resulted in 65 quilts depicting people's memories which are now on display at the Scottish Football Museum, Hampden Park Football Stadium in Glasgow.

Not content with just 65 quilts, Ann has decided to look for donations of 5,000 lap quilts – enough to cover the pitch at

Hampden Park in May 2013! Each quilt should be 40" (or 100cm) square. If you have any old quilts or wallhangings that you no longer need, these are welcome too. A double bed sized quilt is the equivalent of four metre square quilts.

After being photographed from the air, the quilts will be sold, with any remaining being donated to care homes throughout Scotland. The aim of the project is to raise awareness of dementia and how it affects not only the person with the diagnosis but also their families and friends.

Why not get out your sewing machine or your thimble and make at least one quilt for the Hampden Quilt Challenge? If you don't have a suitable pattern, Ann has some to download on her website at www.annhillquilter.co.uk or your local library will have books with patterns in their craft section.

Alternatively, you could get together with a group of friends for an old fashioned quilting bee – many hands make light work, after all.

If you are looking for inspiration, visit Ann's website and look at the Hampden Park quilt gallery section. 337 metre squares have been completed so far – pictures of 288 of them are on the website, showing the range of designs possible, as well as the talents of the quilters. Most of the quilts so far are from Scotland, but there are even a few from as far afield as Australia and New Zealand, so why not ask family and friends in all parts of the world to take part?

Completed quilts can be sent to any of the following:

- Ann Hill, Mouswald House, Mouswald, Dumfries, DG1 4LT
- Alzheimer Scotland, 22 Drumsheugh Gardens, Edinburgh, EH3 7RN
- Quilt Project, Scottish Football Museum, Hampden Park, Glasgow, G42 9BA
- or hand in to your local Alzheimer Scotland office.

Calling all knitters



Alzheimer Scotland's Argyll & Clyde Region is attempting to beat the current world record for the largest hand knitted blanket (non crochet). The current record stands at 557.34 square metres and is held by the ladies of Hatfield Christian Church (South Africa).

By Dementia Awareness Week in June 2012, we want to create a blanket measuring 710 square metres. This blanket will be made up of 71,000 squares, representing the number of people in Scotland in 2010 who had dementia. This record attempt will not only raise awareness but we hope it will also encourage people from all over Scotland and beyond to pass on the skill of knitting to someone they know.

Chris Doogan, our link worker in Oban, is organising and publicising the challenge and already has knitters on board from as far away as Yorkshire and America, as well as all over Scotland. But we need many more people to make it happen.

We are looking to you for help. If you can knit, we would really appreciate you helping by knitting squares measuring 10cm by 10cm. If you don't knit, do you know someone who does and who would like to get on board with this record attempt?

If you can help, please contact Chris Doogan on 01546 605517 or by email at cdoogan@alzscot.org. Chris will send you a pack containing information on the record attempt and what to do with your squares when you have knitted them.

We look forward to hearing from you and working together to bring this record to Scotland.

Fundraising News

Wedding Present



Thomas and Mandy on their wedding day at Strathallan Castle

A donation of £360 was made to our Forget-me-not volunteer project on behalf of newlyweds Thomas and Mandy Brown by Mandy's parents, Mr & Mrs George Mailer. Alzheimer Scotland is a charity that is dear to the hearts of the bride and groom.

Christmas Cards 2011

Thanks to our many supporters who purchased our Christmas cards during the 2011 festive season. We are extremely grateful for your support. We've brought in more than £50,000 from our card sales this year. The most popular design was our Edinburgh card closely followed by Eleven Pipers. Our two gift wrap designs proved to be extremely popular too. We've already started to choose our designs for 2012 so watch this space!

Our supporters are getting younger!

27 year old Kris Rodden and more than 20 of his friends and family took part in a 10k Memory Walk in Glasgow last winter.



At the young age of 59, Kris's mother was diagnosed with Alzheimer's disease. She can no longer take care of herself, wash; clean, dress or even eat without the help of her carers. These seemingly simple tasks which many of us take for granted are a constant struggle for his mother and those who care for her.

Kris organised the sponsored Memory Walk to raise awareness of the impact of dementia and to raise money to support the work of Alzheimer Scotland.

He managed to get the support of several celebrities across Scotland and the UK, including Libby

McArthur, Michelle McManus and Jane MacDonald, who wrote,

'Alzheimer's is a condition that robs us of our loved ones while they are still with us. My heart, strength and love go out to all the amazing carers out there who make a tremendous difference to so many people's lives every single day.'

The participants were delighted when River City actor Tom Urie arrived to lend his support to the event and pose for pictures.

As well as celebrities Kris received the support of generous companies including Eden Springs who donated bottles of water for those taking part to help them complete their 10k challenge.



At the Memory Walk, one of our youngest ever supporters took part. Young Cameron Combe (then just 6 months) was brought along by his Mum Christiana from their home in Beith. Cameron's great grandfather William Thomas Leggat has vascular dementia and three generations of the family took part in the Memory Walk for him.

More young supporters

St Mungo's Mother and Toddler group raised £657 for us by taking part in a 'Toddle Waddle' around Alloa Town. Not only was this a great fundraiser it helped to raise awareness in the local area. Alzheimer Scotland was their chosen charity because we provided support through our day care service to one of the children's grandmother.

Tesco Charity of the Year Partnership – a huge success

Back in the Day Ball – Dundee



Sean Batty with Gillian Messelink (left) and Lucy Christopher

STV weatherman Sean Batty joined forces with the Tesco Customer Service team in Dundee to raise an incredible £19,090 for Alzheimer Scotland at the company's annual fundraising ball. Guests were treated to music from bands Eat the Peach and The Committee and a whole host of fabulous treats.



Alzheimer Scotland staff Pat Brodlie (Angus), Mary Gibson (Dundee) and Bud Baxter (Perth & Kinross) launching the Roadshow vehicle

The Tesco Charity of the Year partnership came to an end on 29 February, with £6.5million having been raised so far across the UK for Alzheimer Scotland and Alzheimer's Society.

The projects being funded through the Partnership are up and running, with the Dementia Community Roadshow having already reached more than 1,000 people in different parts of Scotland. Four of the five new Dementia Advisor posts being funded have now been filled. Tesco have also matched their staff fundraising efforts and donated £75,000 to Alzheimer Scotland which will help us expand the reach of our Dementia Helpline with a new, email-based support service to increase the number of people who can be supported.

Tesco staff have been really inventive in their fundraising efforts and have definitely put the "fun" into fundraising with events such as "Distribution's Got Talent", Bush Tucker trials for senior staff in "I'm a senior team member – get me out of here" and a team of 8 burly men who took turns squeezing into

a Robin Reliant to drive from John O'Groats to Land's End.

Other quirky events that have taken place over the last year included a Zumbathon organised by Tesco Auchinleck and involving 18 Scottish Tesco Superstores, and Inverness stores holding a Smurf bed push event between a number of local Tesco stores.



With golf tournaments, memory walks, abseils, fun runs, skydives, a Kilimanjaro Trek, store fundraising, charity balls, promotions in store and customer donations, this partnership year with Tesco has proven to be a success in raising much needed funds for Alzheimer Scotland and raising awareness of dementia and Alzheimer Scotland in communities all across the country.

Rob Roy Challenge 2012



For the second year running, Alzheimer Scotland is one of the chosen charities of the Martin Currie Rob Roy Challenge 2012, a fantastic fundraising challenge which comprises a 16 mile walk or run from Drymen to Callander followed by a 39 mile cycle to Kenmore. This year's Challenge takes place on **Saturday 23rd June**, with over 700 people expected to take part.

Now in its seventh year, the event is a wonderful way to experience the Scottish countryside at its most beautiful along the spectacular Rob Roy Way, while supporting the work of Alzheimer Scotland and that of our partner charities, NSPCC and WaterAid. Through the sponsorship of individuals and teams, over £352,000 was raised for charity last year, including an incredible £88,000 for Alzheimer Scotland - and we hope to raise even more this year.

Davy Macdonald, Alzheimer Scotland's Development Worker in Oban, was one of the brave participants last year: "I hadn't ever taken up such a challenge before so was pretty nervous as to whether I would even manage to complete it or not. But on the day you just got swept up in the atmosphere of it all and that kept you going – along with the amazing scenery, and knowing that you were really doing something useful to support families living with dementia. That took your mind off the rain and the midgets!"



Davy (centre) with two of his team mates

On completion of the event, teams will be hosted with a sumptuous feast and party on the stunning banks of Loch Tay. After overnight accommodation (camping or nearby hotels), a special breakfast is served on Sunday before teams depart for home. It's a great event to take part in with friends, families or work colleagues, and many companies enter large teams every year as a very unusual but rewarding team-building experience.

We would love even more of our supporters to take part. It's easy to sign up at the Rob Roy Challenge website - www.robroychallenge.com/home/ - which also offers more information about the event and lots of useful tips for training and fundraising. We are also looking for event marshals so if you would like to enjoy the scenery and the fantastic atmosphere (and party afterwards!) but don't fancy taking part in the challenge, why not volunteer to help?

For more details on the Challenge, or to register your interest in volunteering, please contact Lucy Christopher at lchristopher@alzscot.org or tel: 0131 243 1491.

Bend it like Beckham?

In January, a brave team of Alzheimer Scotland staff rose to a challenge from the Tesco St Enoch store in Glasgow. Our team, who had never played together before, took to the football pitch against four teams from Tesco.

Our lads played 10 minute games against each of the four Tesco teams, with only 10 minutes' recovery time between each match. Unfortunately, despite the cracking football skills on display from Alzheimer Scotland, it was a team from Tesco called The Smiths who were overall winners, as well as being integral to organising the tournament.



Chief Executive Henry Simmons in action

I would like to thank each of the players from our team who did a fantastic job despite the cold weather (and the pasting they received in their first match) and to their supporters who came on the day to cheer them on.

Rachel Laming
Community and Events Fundraiser

New Dementia Resource Centres – your help needed

Football Reminiscence Project scores with the People's Postcode Lottery Dream Fund



L-R: Alistair Fergusson (Alzheimer Scotland), Annemiek Hoogenboom & Jo Bucci (People's Postcode Lottery) and Robert Craig (Scottish Football Museum)

Alzheimer Scotland's Football Reminiscence Project, in partnership with the Scottish Football Museum, has been given a fantastic award of £75,000 from the People's Postcode Lottery Dream Fund. The money will help to train volunteers to use historical football nostalgia to stimulate memories, as well as creating a permanent base for the project at Hampden Park, Glasgow

We all know that Scots are passionate about football. We also know that football can be an incredibly powerful tool in helping to trigger other memories. So when we bring football nostalgia to those with dementia it often has amazing results.

Our pilot project showed that photos of a game can help people to remember where they went for a pint before, where they watched it and, in some cases, even conversations that took place during the game.

Alistair Fergusson

Trusts & Corporate Fundraising Manager

We have previously announced the opening of our new Dementia Resource Centres in Helensburgh, Oban, Dundee and Bearsden – centres very much in the community, providing information and support to people with dementia, their partners, families and carers.



Staff teams have now moved into two new resource centres in Greenock and Kirkcaldy and centres in Inverness and Dumfries will be ready to occupy very soon. Work on the Dementia Resource Centre at 1 Nicol Street, Greenock was held up by severe vandalism shortly after we purchased the building. News of the extensive damage reached local and national newspapers and led to offers of support from local people shocked by the damage done to a much needed community facility.

In December, our Fife team moved into new premises at 12-14 Whytescauseway, Kirkcaldy. The new location by the bus station is truly in the heart of the community and will eventually provide space for meetings and events that other groups can use.

In Inverness, we will be opening a Dementia Resource Centre in the heart of Inverness, at 2 Strothers Lane, between the bus and train stations. In Dumfries, we will be moving a few doors along to 8

Gordon Street to a refurbished building which will provide space to 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. We will also provide an advice and information service.

Can you help?

We are actively fundraising to make sure that these Resource Centres will be comfortable, well equipped, relaxed, welcoming spaces for people with dementia and their carers. We would be delighted to hear from anyone who is interested in supporting us through volunteering, fundraising and donations. There are lots of ways to get involved.

If you are interested in supporting our Dementia Resource Centre campaign, please contact:

Inverness

Vera Haringman, Alzheimer Scotland Fundraiser Northern Scotland on 01463 711707 or email: vharingman@alzscot.org

Dumfries

Ailsa Black, Service Manager, on 01387 261303 or email: ablack@alzscot.org

Fife

Julie Penn, Service Manager on 01592 204541 or email: jpenn@alzscot.org

Greenock

Bridget Donnelly, Service Manager on 01475 261100 or email: bdonnelly@alzscot.org

Membership matters

Not everyone who reads Dementia in Scotland is a member of Alzheimer Scotland – you may have picked up this copy in one of our Dementia Resource Centres, or in your public library or GP practice, or be reading this online. If you are not already a member, please read on to find out how, by joining Alzheimer Scotland, you can help make sure no-one goes through dementia on their own.

By becoming a member you will be helping Alzheimer Scotland in so many ways:

- We use membership subscriptions to help fund our work, especially in four key areas – our Dementia Helpline, Dementia Advisors, Dementia Nurses and Dementia Research
- You will add strength to our campaigning voice – we are stronger together
- You demonstrate belief and support in our cause and the aims we have
- You might get involved in surveys and consultations that give us valuable information

for policy and publication development

- You could become part of our governing council and help grow and sustain the charity
- You might like to volunteer at a branch or service or even get involved with fundraising.

Anyone (except Alzheimer Scotland staff) can become a member – you may be a person with dementia, a partner, carer or former carer, family member or friend. You may be a student, or a health or social care professional. Whatever your connection or profession, by becoming a member of Alzheimer Scotland you send a message that you care about people with dementia and want to be part of the leading dementia charity in Scotland.

Becoming a member is easy, you can join online at www.alzscot.org or you can call the fundraising department during office hours on 0131 243 1453. We have a variety of membership options (ordinary, reduced rate, group and corporate)

and can help you choose the one that is right for you.

Your membership brings benefits for us but we also like to give something back! Members get discounts on training, the right to vote at our AGM, a free copy of our quarterly newsletter *Dementia in Scotland* and a free copy of our Annual review.



So please think about becoming a member or, if you are already a member, why not encourage other people to join us?

Shona Blakeley
Head of Fundraising Development

Continued from page 8

Where will the new Link Workers be based?

In some locations we are adding to our post diagnostic support services by extending the working hours of existing staff; in other areas there will be completely new posts. Those agreed so far include:

- 3 full time posts in mid Highland while a further 3 posts have been filled in SE Highland, covering Inverness, Nairn and Badenoch & Strathspey; we also expect a new full time worker in Sutherland as well as extra resources to extend post diagnostic support through our Caithness based services.
- We are currently recruiting a new worker in Midlothian with a further 3 posts coming up soon in the Scottish Borders. A third part-time post is now up and running in Lanarkshire.
- In Argyll and Bute, our three new Link Workers will be based in Oban (to reach the islands); Campbeltown for the peninsula and islands; and Cowal. This will bring our team in Argyll and Bute to 6 Link Workers and one Post Diagnostic Services Manager.
- 3 full-time posts in Perth and Kinross.
- A link worker and “community connections” programme in Stirling and Clackmannanshire.

Diary dates

Events hotline
0845 260 0789
events@alzscot.org



Dementia Awareness Week

18-24 June 2012

The theme this year is "Creative minds" so look out for some really exciting and stimulating events in your area. Our Dementia Awareness Week conference will follow the creativity theme. "Creativity and dementia: policy and practice" will take place in Glasgow on Monday 18 June.

Saturday 21 April, Glasgow Opera Experience

If running is not your thing, why not come along to a night of music, dance and storytelling at Glasgow Cathedral, featuring Martin Aelred, contemporary classical singer, with special guests including Scottish Opera's Forget-me-not Choir. Tickets £10 from <http://www.wegotickets.com/event/156354> or contact Rachel Laming, Community and Events Fundraiser, Alzheimer Scotland, 49 Milngavie Road, Bearsden, Glasgow G61 2DW; tel: 0141 946 0966; Email: rlaming@alzscot.org

Thursday 31 May, Dirleton Golf Event, Archerfield Dirleton Links

Tee off your summer with Alzheimer Scotland's fundraising Golf Event. Drive and putt your way across the course and finish the day with a two course dinner, auction and raffle. The event will tee off with a Shotgun Start and will take the form of a Texas Scramble (stroke play). Tickets are £600 for a team of four. Contact our Events hotline for more information:

Events hotline 0845 260 0789;
events@alzscot.org

For some of our active events we require a registration fee and minimum sponsorship – please ask our Events Team for details. See our website for updates and new events coming up.

Sunday 15 April, Edinburgh	Rock and Roll Edinburgh Half Marathon 2012
Saturday 21 April, Glasgow	Opera Experience (see opposite)
Sunday 13 May, Glasgow	Glasgow Women's 10k
Saturday 26/Sunday 27 May, Edinburgh	Edinburgh Marathon Festival of Running (Saturday: 5K and 10K; Sunday: Marathon; Relay Marathon and Half marathon)
Sunday 27 May, Central London	Bupa London 10,000
Thursday 31 May, Dirleton	Golf event, Archerfield Dirleton Links (see opposite)
2-7 June	West Highland Way Challenge
Sunday 10 June, South Queensferry	Forth Bridge abseil
Saturday 23 June, Drymen	Rob Roy Challenge (see page 17)
Saturday 14 July, Bellahouston Park, Glasgow	Glasgow Big Fun Run (5K)
Sunday 15 July, Holyrood Park, Edinburgh	Edinburgh Big Fun Run (5K)
Sunday 12 August, Aberfeldy	White Water Rafting