

Issue 67 - Sept 2009

Dementia in Scotland Newsletter

£1.50 (Free to members)



Alzheimer Scotland
Action on Dementia

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Editorial

Summer is traditionally a slightly quieter time with so many people, including our politicians, being on holiday. The number of meetings, conferences and consultations tends to drop because people are away. Not this year.

Perhaps it's just as well that we didn't get the "barbecue summer" the weather forecasters were promising earlier in the year because things have been hot enough in the dementia field in Scotland.

In late May, the Care Commission/Mental Welfare Commission report on the quality of care in care homes, Remember I'm still me will have made for uncomfortable reading for some care home managers. See page 11 for some of the key findings and comment by Chief Executive, Henry Simmons.

In early June, Dementia Awareness Week brought the usual busy round of activities across the country with our annual conference attracting almost 400 delegates to a two-day event which focussed on personalisation. See Kate Fearnley's report on page 7. A key feature of the conference was the announcement by Minister for Public Health, Shona Robison MSP, that the Scottish Government planned to develop a Dementia Strategy. Alzheimer Scotland will be a key player in the development of the Strategy - see page 3. With a deadline of Easter 2010, it looks like autumn and winter will be busy too.

Mid to late June saw a series of roadshows in different parts of the country, consulting on a proposed Charter of Rights for people with dementia and carers and inviting attendees to contribute to the development of a mid-term manifesto, due to be launched to coincide with World Alzheimer's Day.

Most recently, those readers who peruse the "situations vacant" columns in the Herald and Scotsman will have seen our advert for Dementia Advisors in several parts of Scotland. These advisors will provide a local point of contact for people with dementia and their families and friends, at all stages of their journey, from diagnosis through to end-of-life. As well as helping individuals and families, the advisors will support communities to become more dementia-friendly. The new network of advisors will help us ensure that no-one goes through dementia on their own.

Underpinning all this activity are the amazing efforts of those people who do all sorts of activities to raise much needed funds for our work including, now, our team of Dementia Advisors. As usual, this issue features just a few of our many supporters.

Maureen Thom
Editor
Dementia in Scotland



Warning of “dementia timebomb”

In an open letter in July, 31 of the country's leading scientists and experts called on the government to end “years of underfunding” in dementia research or risk paying the price of not doing so, as the numbers of people with dementia is predicted to double within a generation. They asked the government to commit to tripling its annual support for dementia research to £96million within five years. “If we can work out how to delay the onset of dementia by five years, we could halve the number of people who die with the condition.”

European study identifies higher number of people with dementia

A Europe-wide study has shown an increase in the prevalence of dementia, compared to previous studies. The research from the European Collaboration on Dementia project (EuroCoDe); financed by the European Commission and coordinated by Alzheimer Europe, is the largest collaborative study to date in this field.

While the findings from the EuroCoDe study are largely consistent with the earlier Eurodem study, the prevalence of dementia in women aged 80

and over is higher than previously reported. This is because there was a lack of information on this age group available for earlier studies.

Alzheimer Scotland has revised current estimates of numbers of people with dementia in Scotland in response to this new evidence.

Information on the number of people with dementia in Scotland is available on our website at www.alzscot.org/pages/statistics.htm

For further information contact:

Lindsay Kinnaird

Policy & Research Officer

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Dementia Strategy on the way

Having previously declared dementia to be a national priority for Scotland, the Scottish Government stepped up the pace at the end of May by announcing that a Dementia Strategy is to be developed which will provide “a robust, sustainable infrastructure for people with dementia and their carers”.

Shona Robison, Public Health Minister, made the announcement on the same day that the Care Commission and Mental Welfare Commission launched their joint report on the quality of care in care homes, *Remember I'm still me* (see page 11). The Minister described the report as “deeply shocking”, saying that the Government accepted all the report's recommendations and would meet the Commissions and Scottish Care (a national body representing care homes) to discuss the issues as a matter of urgency.

Welcoming the announcement of a strategy, Alzheimer Scotland's Chief Executive Henry Simmons said, “We look forward to playing a key part in helping to shape this new strategy, which we hope will encompass the full journey of life with dementia: from post-diagnostic and community-based support through to long-stay and palliative care.” He went on to stress the importance of having a significant Change Fund of at least £15 million in place to support the new strategy; this

had been pivotal in ensuring the success of other strategies such as the *Same as You* in the learning disability sector.

The Government intends the Dementia Strategy to build on developments such as the establishment of the Ministerial Dementia Forum, the creation of clear targets for the NHS to improve the diagnosis and treatment of dementia, the piloting of post-diagnostic support in three NHS board areas, and work on public information and awareness raising.

Five broad workstreams have been established:

- Treatment and managing behaviour
- Assessment, diagnosis and patient pathways
- Improving the general service response to dementia
- Rights, dignity and personalisation
- Health improvement, public attitudes and stigma

The Strategy will be prepared by Easter 2010 and will be developed by government officials working in consultation with members of the Dementia Forum and other partners. Alzheimer Scotland, members of the Scottish Dementia Working Group, and carers are involved in each of the workstreams. Alzheimer Scotland will use the results of our consultations on the draft Charter of Rights and manifesto to inform the development of the Dementia Strategy.

Words into Action on Dementia

In mid to late June, Policy Director Jan Killeen organised a series of roadshows and an online consultation under the banner *Words into Action*. The consultation invited people to comment on a draft Charter of Rights for people with dementia and carers and a mid-term manifesto to be used to influence the main political parties who are in the process of developing their own manifestos for the next election.

The consultation was successful, with 400 responses received and incorporated into a revised draft of the Charter and informing the development of the manifesto which will be launched at the World Alzheimer's Day lecture on 22 September.

An article on the Charter will appear in the December issue of *Dementia in Scotland*.

Alzheimer Scotland

Dementia Advisors

We are well on our way to setting up our new Dementia Advisor initiative which will link into the already excellent work of our local services and the Dementia Helpline and allow us to support even more people with dementia and their families and carers through the illness.



This problem is compounded by people often being offered services only once the person's condition has worsened, often months or even years after diagnosis. By this point, the person with dementia and his or her family may have become cut off from the community supports previously provided by friends and neighbours and through participation in hobbies and leisure activities.

The solution?

Alzheimer Scotland has responded to these issues by advertising for 16 Dementia Advisors, the first stage in our plan to establish at least one Dementia Advisor in every local authority area in Scotland. Each Advisor will provide a local point of contact for people with dementia and their families and friends, at all stages of their journey, from diagnosis through to end-of-life. They will provide information on support services available locally for both the person with dementia and his/her carers and family members, offering advice and signposting as and when required. Advisors will also provide support to local communities to help them become more dementia-friendly and to increase their capacity to support those living with dementia.

Interviews will be held in late September and October and we hope that some of the successful candidates will be able to attend our AGM in November where the initiative will be officially launched.

The problem

Alzheimer Scotland believes that no-one should go through dementia alone. After receiving a diagnosis, many people with dementia and their families face a challenging future, coping with the diagnosis and its prognosis. Added to this challenge are problems with navigating the maze of services provided by social work, the NHS, private and voluntary agencies. Many individuals and families report not being aware of the services and support available to them, when they need them.

“After the diagnosis, we found ourselves out on the pavement with no idea what to do or where to turn to for help.”

“I had to go through the Yellow Pages to try to find someone who might give me some help looking after my mum.”

Taking control of your own care

Below you will find articles about two new projects aiming to help people with dementia and their families develop more creative solutions to their care needs.

Self Directed Support Anyone?

People living in Ayrshire are now able to benefit from the development of an innovative project in the area. The Scottish Government have funded Alzheimer Scotland to deliver a two-year pilot demonstrating best practice in supporting people with moderate to severe dementia and their families facing the prospect of long stay care to design creative, personalised solutions using self-directed support, as an alternative to institutionalised care.



Yvonne Stewart has been appointed as the new Self Directed Support Project Manager. The pilot will cover East, North and South Ayrshire, which combined have approximately 4,500 - 5,000 people with dementia.

What is self-directed support?

Self-directed support is when a person chooses to arrange some or all of their support services instead of receiving services via the local authority social work or housing department. It is for people who wish to have more choice, flexibility and control over their care so they can live at home more independently.

Once assessed by your local authority you will get a sum of money to spend on the support you need instead of receiving council services. If you wish you can choose to organise some of your own support and also receive some council services.

Most people who use social work services can access self-direct support. Currently though only a very small percentage of people with dementia (estimated at 0.1%) and their carers have accessed self directed support funding in Ayrshire. We want to change this.

Yvonne said "I am so pleased to be involved in this ground breaking project; this will provide a real opportunity to work closely with families to provide creative alternatives to long term care for their loved ones. It's an exciting time for everyone concerned and a step towards providing more personalised support to people with dementia in their own community"

Self directed support is about people making the choice to take greater control of when and where and how their social care services are provided. Yvonne added "I am passionate about people having choice and control in their lives and to determine where and how they live and I am keen to support people to attain a truly person-centred package of support that reflects their needs". Fortunately the pilot site benefits from having well-established Alzheimer Scotland services in all three Ayrshire authorities and Yvonne is looking forward to working closely with each of them.

For more information contact:

Yvonne Stewart
Self-Directed Support Project Manager,
Alzheimer Scotland, 43 West Portland
Street, Troon KA10 6AB
Tel: 01292 317 665
Email ydstewart@alzscot.org



Scottish Awards for Business Excellence

Alzheimer Scotland was delighted to receive a 'Committed to Excellence Award' presented by Sir Andrew Cubie at the 16th Annual Scottish Awards for Business Excellence held in the EICC on the 19 May 2009.

Julie Miller and Barbara Sharp from our Practice Development Team and Tricia de Beaux our Human Resources Manager attended the event which celebrates the most rigorous and prestigious business awards in Scotland. These awards allow organisations across all sectors to assess performance and to benchmark achievements against other organisations. In achieving awards participants have shown an outstanding obligation and enthusiasm to continuous improvement.

Another highlight of the day was the debut of Quality Scotland's 'Ambassador Award' created to recognise those who have continually represented Scotland as an 'Ambassador for Excellence' and assisting Quality Scotland to 'Make Excellence a National Characteristic'. The award was presented to the Voluntary Sector Network (VSN) of which Alzheimer Scotland is an active member. Each member present was invited to the stage to be given the award. Both awards are now proudly displayed in our National Office in Drumsheugh Gardens.

For further information contact Julie Miller on 0141 418 3932, jmiller@alzscot.org

Julie Miller
Practice Manager, Practice
Development Team

Facing Dementia Together



Working with East Renfrewshire Community Health & Care Partnership and with Renfrewshire Council and Community Health Partnership, Alzheimer Scotland's "Facing Dementia Together" pilot project is bringing the personalisation agenda into the world of dementia services.

This project supports, enables and empowers people with early dementia, together with their carers/supporters, to be able to take control of the services they need, now and in the future, and to work with their local authority and NHS to develop the systems and approaches to make this a realistic option.

One of the barriers for people with dementia is the widespread lack of post-diagnostic support, which denies them the opportunity to develop their understanding of the illness, enhance their coping skills and improve their chances of being cared for in their own homes for longer. People with dementia need the tools to become active participants in their own care and to be supported to maintain or recover control in their lives as much as possible at each stage of the illness.

It is particularly important that this support should be provided immediately following diagnosis while the person with dementia has the capacity to make decisions and plan ahead. The "Facing Dementia Together" project will provide information and support to help the person and their carers/supporters to understand and come to terms with living with dementia, and to put in

place legal arrangements to maximise their control over future decisions made on their behalf (e.g. powers of attorney, advance statements).

Using person centred planning tools, staff will assist people with dementia to realise their aspirations and fears, and to plan ahead for their future needs, discuss options for future care and set out their wishes for the future. The project aims to help people to think creatively about the support they might require and to make use of 'natural supports' including support from family, friends and community.

Tracy Gilmour, Practice Manager and Michelle Shaw, Project Worker both took up post in February.

*They can be contacted at:
Alzheimer Scotland @ Undercover,
56 Kelburn Street, Barrhead, G78 1LR.
Tel 0141 876 9523,
e-mail tgilmour@alzscot.org or mshaw@alzscot.org*

Living Positively with Dementia

Alzheimer Scotland's Argyll & Clyde Region were this year given the challenge of organising not one, but two conferences by Regional Manager, Jan Johnston. After a few excuses, the development worker got together a conference team and set about organising the events.



The conferences entitled 'Living Positively with Dementia' were well attended by people with dementia and their carers as well as various care professionals.

The day kicked off with a drama production which introduced the theme of how things are for many people with dementia and their carers at present, but went on to encourage the audience to look at how things could be more positive.

Following a welcome by MSPs in both areas, people with dementia then took to the stage and spoke with passion about their journey so far. Workshops gave people more opportunity to get involved, as well as hearing about good practice across the region.

A second drama production got the audience back in the right frame of mind for the afternoon and again

had enthusiastic participation from all delegates. Our local carers spoke about the good and the bad, leaving the 'professionals' with a few questions to ponder on.

The day was rounded off positively by Alzheimer Scotland's Policy Director, Jan Killeen in Dumbarton and Personalisation Director Kate Fearnley in Inverclyde.

Service Managers, Lorraine Robertson and Bridie Donnelly and Regional Manager, Jan Johnston were encouraged by the participation and interaction between all delegates. Evaluation from the days were very positive with delegates commenting on the stimulating yet informal atmosphere. Many spoke of the positive impact they felt the day had on their future practice and how they would be more active in listening to the views of people with dementia.

Jean Armitage
*Development Worker,
Argyll & Clyde Region*

Personalisation conference success

Alzheimer Scotland's two-day Dementia Awareness Week conference on 1-2 June was very successful, with almost 400 people attending. Participants included many people with dementia and carers, for whom we were pleased to be able to provide 27 free places, as well as a wide range of professionals such as social workers, psychiatrists, Care Commission officers, service managers, nurses, support workers, and planners and commissioners.

The conference title was *Let's get personal: personalisation and dementia*. It addressed best practice in dementia services and how to personalise services by putting people with dementia and their carers in control; so that they know how much money there is to spend on their support and can choose the services which fit best with their lives.

There was a very wide-ranging programme of speakers and workshops. The first day focussed on post-diagnostic support and on how to change the way services are organised,



so that people have choice and control rather than having to fit in with what's available. Duncan Mackay, Head of Social Work Development in North Lanarkshire Council, set the tone in his opening keynote speech about how the council has been working on transforming the way they commission their services to make them more personalised.

Day two addressed long stay care and palliative care, and featured a keynote address by Shona Robison MSP, Minister for Public Health,

who told the conference about the Scottish Government's proposal for a National Dementia Strategy (see page 3 of this newsletter) which she said would provide a 'robust, sustainable infrastructure for people with dementia and their carers'.

Conference presentations are available on our website at <http://www.alzscot.org/pages/dementia-awareness-week-conference-presentations.htm>

Kate Fearnley
Director of Personalisation

Fundraising News

Fundraisers extraordinaire



Sheila, on the right, with two of her ex-colleagues who meet up every year to have their Tea Day.

Sheila's mum had dementia and she looked after her until she passed away in 1997. Thereafter, Sheila has been holding tea parties to raise funds for Alzheimer Scotland. The parties started as small affairs: asking friends and neighbours to the house for tea/coffee and cake and asking them to leave a donation. Her first party raised £55.40 back in 1997.

She then started to ask friends and colleagues at work for donations of home-baking, unwanted toiletries and

gifts and over her years the parties have become bigger and bigger. Her latest party, held in May at St Serf's Church Hall in Edinburgh, brought in a remarkable £955.00 to help support services in Lothian.

Sheila could not hold these parties without her trusty gang of volunteers, made up of friends and ex-colleagues from her Social Work days at Westfield House. They get together each year to ensure that the event is a success even though they don't see each other from one year to the next. At the end of the afternoon they sit down together and have a glass of bubbly, provided by Sheila's hubby, and count the proceeds!

Each member of the group has been touched directly or indirectly by dementia and they are all passionate about raising funds for Alzheimer Scotland.

Total raised over the years - an amazing £4,524.86! Thank you ladies for all your hard work!



Events Manager Moira Lawrance receiving a cheque from Jonathan Shawcross

Cheques galore

Our staff are delighted to be asked to receive cheques for monies raised by our supporters. Recent donations include:

£455 from Di Burchell from Dundee who part in First Monster Challenge

£500 from Perth Inner Wheel to support work in the Perth area

£1818 from staff at FG Burnett in Aberdeen who took part in the Aberdeen 10k

£4890 from Jonathan Shawcross from the Royal Bank of Scotland who took part in the Edinburgh Marathon

It's a tough job



Earlier this year, The Hotel Squadron chose Alzheimer Scotland to be the beneficiary of their annual Ladder Climb at the Scottish Fire Services Training College in Gullane. They managed to raise a magnificent £1100 for Alzheimer Scotland's Dementia Helpline, along with an additional £341 from sponsorship gift aid.

Shona Blakeley and Jenny Wilson from our Fundraising Team had the task of attending a dinner with the Squadron where they collected a cheque. Judging by their expressions they enjoyed the experience!

Straight down the middle

The ladies of Strathaven Golf Club recently raised £500 at their open day for Alzheimer Scotland and have asked that the money be divided between the Dementia Helpline, our research fund and our South Lanarkshire services. Next year's Lady Captain has also chosen us for her charity and so we will be benefiting even more in 2010 from the Club and its fundraising efforts. The Club were also interested to hear about our plans for recruiting Dementia Advisors (see page 4) and were pleased to hear that some of their funds will go towards supporting a post in South Lanarkshire.

Arlene Crockett
Service Manager, Motherwell

Masonic Magic for Midlothian



Left to right: Alaine Chalmers, Hazel Johnson, Jim and Anne Pryde

The Midlothian Service of Alzheimer Scotland were delighted to be invited to collect a cheque from The Masonic Lodge, Kilwinning 10 Dalkeith. On arrival, Alaine and I were welcomed into the heart of the social. We were told £3,000 had been raised - £1,200 was by Craig Gordon who ran the half marathon and Margaret Gordon and Anne Pryde who ran the 10k. A further £1,800 was raised through the brothers, family and friends making a grand total of £3000.

Reeling from the shock, we soon entered the dance floor and danced with several of the guests to the band, Two's Enough, two local guys who were absolutely fantastic. The master Mason, Jim Pryde gave a heartfelt speech and then he and his wife Anne presented the cheque to us. After a huge thanks and short speech explaining why fundraised income is so important and how the money will be used to benefit people with dementia and their carers in Midlothian, a bountiful buffet fit for royalty was served.

After the buffet, Bingo was played (they play a lot faster than in day care - Alaine had to take some of my books), a raffle was held, and then the band played on. There was much dancing and singing, the whole night had a feeling of fairy dust being sprinkled everywhere, the atmosphere was electric and fun and laughter was had by all.

Personally and on behalf of Alzheimer Scotland, I would like to thank all the people who were involved in this major fundraising event and who were not able to attend the presentation and, once again, thanks for a wonderful night.

Hazel Johnson
Service Manager

West Highland Way Walkers

Every year, people brave the midges, the weather and blisters to walk the 95 miles of the West Highland Way between Milngavie and Fort William to raise funds for our work. Here are just a few of them...

In memory of Grandpa Scotland



Isabel Evans and her parents walked the West Highland Way to raise money for Alzheimer Scotland. Isabel said "It was the first charity that I thought of as it helped my Granny so much when my Grandpa was dying of this horrible disease". Here is her account of the experience:

"The West Highland Way is one of the most rewarding and beautiful things I have ever done. The scenery was breathtaking and all the evenings were spent watching the sunset over yet another incredible landscape. Not only was the walk good for all of those things, it was also a great opportunity for me and my parents to raise money, and many people contributed very generously even in these difficult times.

We saw fellow walkers in the evenings in pubs or restaurants and swapped stories (of which there was an endless supply.)

I am very aware of lucky I am to have been able to complete this walk even though it was tough, (as my feet kept reminding me in the evenings,) but it was made worthwhile not only by the people we met, but the things we saw, including deer outside our window and horses riding The Way, the places we stayed and how welcoming they were, and my parents who walked it with me. I enjoyed the walk thoroughly throughout and I hope that I will be able to do something of a similar nature in the future."

Many thanks to Isabel who raised nearly £1200 in sponsorship.

Three men from Wishaw did the walk to raise funds for us in May in atrocious conditions.



Left to right: Eric Davis, Raymond Rafferty and Brian Taylor

Raymond and Eric both work for Howdens UK Ltd and their colleagues played a huge part in raising a staggering £3644 in memory of Raymond's mum, who passed away last November.



Ada McIntosh (left) and her sister Babs Ritchie walked the West Highland Way in terrible weather in May amid five days of torrential rain and high winds! They have raised £1735 so far and hope to get some matched funds from Ada's employer, Lloyds Banking Group.

Men's 10k



This "men only" 10k running event was held in Glasgow on Father's Day - Sunday June 21 - with 60 men taking part on our behalf, including Craig Laird and Alan McManus. Alan's kilt proved to be a great help to the boys - as they ran as the crowd shouted encouragement. Not sure if the sporran was a wise addition to a runner's outfit though!

Dumbarton Carers Cheese & Wine Evening



Date for your diary

The Annual General Meeting of Alzheimer Scotland will take place on Friday 6 November at the Thistle Hotel, Cambridge Street, Glasgow. Members will be sent further information and papers in October.

Christmas cards 2009

It's that time of year again! Christmas cards are now available online from our shop at www.alzscot.org or from the fundraising department on 0131 243 1453. Members will find an order form enclosed with this issue of *Dementia in Scotland*.

West Dunbartonshire Carers' Group held a Cheese and Wine Evening on Thursday 11 June 2009. The event was held to celebrate Dementia Awareness Week and to reach out to carers who had not accessed the group before.

Alzheimer Scotland Council member Barbara Barnes gave a presentation on the history of the group, which has now been running for 24 years and

has supported many carers to seek help and advice, and is still going from strength to strength.

We had information points around the room, with areas for carers to make suggestions for future topics at meetings and ideas for the summer outing. We had some fun with raffles, with prizes for a lunch at a local hotel and a guided tour around a local distillery.

All in all, a very successful evening, with some carers attending for the first time. Thanks to Barbara, Liz and Sandra, our dedicated volunteers, who helped make the evening run smoothly, from transporting people to/from the event, organising food/drinks, music, and selling raffle tickets.

The group takes place on the 2nd Thursday of every month. We meet in the Elm Centre, 7 Eastfield Place, Dumbarton, G82 1EB (7.30 pm - 9.30 pm). For further information, please contact Margaret Oliver, Carer Support Worker, (01389) 733102 or email moliver@alzscot.org.

Jordanhill School Charity Fundraising

Jordanhill School in Glasgow has a long tradition of raising funds for charity and this year Alzheimer Scotland was the lucky recipient, to the tune of an amazing £19,000. Regional Manager, Sarah Burgess and Service Manager, John Kelly are shown below receiving the cheque from two of the pupils.



All aboard!

The Stirling and Clackmannanshire Branch enjoyed a day out on the Union Canal and the Falkirk Wheel on Wednesday 22 July courtesy of the Seagull Trust. We have enjoyed a number of these trips recently and are grateful to the Seagull Trust for their superb care and attention. This time 24 of us were piped out of the boathouse and over the Falkirk Wheel. If you live in the Stirling area and are interested in joining us for any of our social events you can contact us through the Bridge of Allan office on 01786 831171.



Obituaries

We do not usually include obituaries in Dementia in Scotland but we wanted to mark the passing of two people who gave so much of their time and energy to supporting our work.

David Anderson

We were very sad to hear that David Anderson had passed away recently after a brief illness. David had served on the Council for Alzheimer Scotland for three years from November 2002 to November 2005. I first met David in 1995 when we cared for his late wife Esther at the day care centre in Dumfries. David was always happy to be involved with the service and regularly attended Christmas parties. As he was accomplished at playing the bagpipes he was often roped into playing at various events, which he did with no hesitation. Throughout the years David kept in touch with the service and would pop in to see how everybody was getting on. He was a great ambassador for the organisation, all who knew him will remember him

with fondness and his visits to the office will be greatly missed. Our condolences go out to his family at this sad time.

Julie Barron

Regional Manager - Ayrshire and Dumfries and Galloway

Marion White



Marion receiving her Certificate of Recognition in 2007.

We were also saddened to hear of the sudden but peaceful death of Marion White. Marion had volunteered on the Dementia Helpline since it started 20 years ago, most recently providing support and advice out of hours to less experienced volunteers in her role as

a Team Leader. She was also a great source of support to the staff involved in running the Helpline. Her untimely death has touched many of us.

Over the years, Marion suffered many health problems and her common sense and practical approach to life and its difficulties was a real inspiration. After having a heart bypass operation some years ago, Marion decided to abseil off the Forth Bridge, raising a great deal of money for Alzheimer Scotland, and she became even more well known in her adopted home town of Peebles as a result. Marion was one of the stars of our 10th anniversary film where she described her reasons for getting involved with the Helpline. On being asked why she'd stayed involved so long she said "I'm still here because I've not found a good enough reason to leave".

Our thoughts are with Marion's sons and daughters.

Elaine Harley

Helpline Manager

Likes cats; likes milk - quality of care in care homes in Scotland

Remember I'm still me



Readers may have seen press coverage of a joint Care Commission/ Mental Welfare Commission report on the quality of care for people with dementia living in care homes in Scotland. *Remember I'm still me* reported the findings from a series of unannounced visits to 30 care homes across Scotland, between August 2008 and March 2009.

The report highlighted a range of concerns, including:

- the excessive use of drugs used to control behaviour, with 75% of people taking "psychoactive"

drugs, given for behaviour problems, depression or insomnia

- the lack of regular medication reviews
- a lack of staff knowledge about the life history and individual needs of people in their care, with only 24% of people having an adequate record of their life history. One person had just "likes cats, likes milk" recorded in the personal history
- many people rarely leave their care home. Around half of the people involved never left their care home to go outside.

The report also noted that activity was not tailored to individual interests and activity co-ordinators were not always trained or supervised in their role. Lack of transport and failure to think about how best to use people's money did not help the situation.

Responding to the report, Henry Simmons, Chief Executive of Alzheimer Scotland said, "People with dementia must be afforded dignity, respect and liberty within the care home setting. It is appalling that almost 50% of people

in this report had no opportunity to go outside of the care home at any point. The study reported that only a small percentage of people with dementia have any freedom of movement or access to positive activities. This is as great a detriment to their quality of life as inappropriate medication or inadequately trained staff. These problems should not be tolerated and cannot be allowed to continue."

"In addition, we are particularly disturbed that the inappropriate prescribing of anti-psychotics continues to take place in Scotland's care homes. These drugs are often wrongly used to control the behaviour of people with dementia and have extremely harmful side effects. We estimate that inappropriate prescribing of anti-psychotics costs Scotland between £5 million and £8 million per year".

Remember I'm still me may be downloaded or viewed on both the Care Commission and Mental Welfare Commission's websites at www.carecommission.com or www.mwscot.org.uk

Agnes gets involved

Agnes Houston, vice-chair of the Scottish Dementia Working Group, has been invited to join the Care Commission's Involving People Group (IPG) which is made up of people who use care services and informal carers. The Group meets around four times a year and aims to influence the inspection of care services and to give their opinions and advice on other policies and procedures, all with a view to improving quality of care.



Agnes (60) is a former nurse who was diagnosed with early onset Alzheimer's disease three years ago and has

experienced dementia not only from living with the condition herself but also through caring for her late father. Agnes regularly speaks at conferences and meetings to raise awareness and lobby for improved services for people with dementia. She is particularly keen to see care home staff use simple but effective techniques like memory books and photographs to trigger memories in residents and also to help staff to know the person they are caring for. Since her diagnosis, Agnes has been developing her own memory book, detailing her life history and the things that are important to her.

If more care home residents and/or their families were supported and encouraged to develop memory books, it could greatly improve care staff's knowledge and understanding of the people they work with - so they don't "forget the person inside the dementia" as the *Remember I'm still me* report emphasises.

If you use a care service, or are caring for someone who does, and are interested in taking part in the Involving People Group, you can contact the Care Commission by:

Website: www.carecommission.com - have my say
Tel: 0845 603 0890;
Email: equality@carecommission.com
or write to the Care Commission,
Compass House, 11 Riverside Drive,
Dundee DD1 4NY.

Couples still wanted for research project

Back in March, readers were invited to volunteer for a study being undertaken by Alzheimer Scotland Council member Lynda Hogg into how living with a diagnosis of dementia affects couples' relationships. There was a good response but Lynda would still like to hear from more couples. Both members of a couple have to be willing and able to participate.

If you and your partner would be interested in taking part in this study, contact Lynda Hogg c/o Information Department, Alzheimer Scotland, 22 Drumsheugh Gardens, Edinburgh EH3 7RN; tel 0131 243 1453; email alzheimerscot.org. Your contact details will be passed on to Lynda who will then get in touch with you to discuss the project further.

Letter to the Editor

Following the recent death of my father, I have been dealing with his financial affairs and would like to share the following information which may be of benefit to other carers in the future.

The website www.mylostaccount.org.uk provides a free service by The British Bankers Association, The Building Societies Association and National Savings and Investments who together represent most of the firms offering savings and current accounts in the UK. They provide a simple form online which, when completed, can trace lost accounts and savings.

Hopefully this will be of assistance to others.

*Kind Regards
Eileen Smyth*

Forget-me-Not Volunteer in action

In March, Dementia in Scotland announced the Forget-me-not project which was set up to recruit volunteers to befriend and support people with dementia living in care homes in Glasgow. Co-ordinator Fay McCormick has sent in this short account of a day out with one of the volunteers and a resident. Names have been changed by request. It illustrates how someone living in a care home can be enabled to get out and about and do things she enjoys, the sorts of activities we all take for granted but which so often are denied to care home residents, as the *Remember I'm still me* report showed.

"I had a great day out with Liz. Took her to Boots for a makeover and to buy some new makeup. She has been a lovely looking woman in her day. The girl who did the makeover was really nice and gave Liz lots of free gifts at the end, more than I think she is supposed to! Liz was delighted.

Then we went for lunch - stayed in the St Enoch Centre due to the weather. Had a good look round all the shops. Left there when the rain went off and went to Frasers to meet my work colleagues. It was great for Liz who had plenty of attention and chatted away quite the thing - a bit muddled at times but she got there.

We then went to Princes Square for a coffee and people watch. It was full of young children and Liz seemed to light up watching them. I'm on holiday next week and don't know what my movements are but have said that I'll collect Liz one day and change the time so that she is out for pre-theatre, and hopefully a glass of wine.

Bye for now, Angela."

If you'd like to know more about the Forget-me-not volunteer project, please contact Fay McCormick, Alzheimer Scotland, 81 Oxford Street, Glasgow G5 9EP; Tel: 0141 418 3930; email: fmccormick@alzscot.org



Alzheimer Scotland
Action on Dementia