

# A year of progress and achievement

**Report on the activities of the SDWG  
1 October 2008 – 30 September 2009**

## OCTOBER 2008

### 3rd UK Dementia Congress

Lynda Hogg, Ross Campbell, Agnes Houston and Martin Sewell flew down to Bournemouth early in the morning on 29 October for this two day conference.

It is the largest dementia conference in the UK with nearly 800 delegates. There was a large choice of talks and workshops, many of which were excellent, and it was very worth while spending two long days getting there and back. The highlight of the conference was meeting Terry Pratchett and hearing his closing speech.



We also launched our new poster, featuring Edward's cartoon of Al McZheimer, which went down well.

## Visit to Chinese Healthy Living Centre

Pat McGonigal, James McKillop and Edward McLaughlin went with Jenny Douglas to Glasgow's Chinese Healthy Living Centre to celebrate its re-launch. This was to continue a link Jenny had made, along with Margot Sweeney (Glasgow Involvement Officer), to look at ways of working more closely with people affected by dementia in black and minority ethnic communities. We were very shocked and saddened to hear of funding cuts the following March which closed the Centre. We still intend to work with the Chinese community in other ways.

In November, Jenny stood in for Agnes Houston at the Golden Jubilee Hospital's Disability Reference Group to build further links with members from minority ethnic groups.

SDWG are looking at ways to do some dedicated work in Glasgow and Edinburgh as a start to progressing our work with black and minority ethnic communities. Lynda Hogg, with Committee Co-optee, Katrina Balmer, Jenny and Alan Midwinter (Edinburgh's Early Onset service) have discussed ideas as a starting point for work in Edinburgh. We also attend networking events organised by NHS's Mental Health & Race Equality Unit as part of this early networking. Early discussions have indicated a need for greater awareness-raising about what dementia is and what is there to help. We are planning to work alongside partners to respond to this immediate need.

## Parliamentary Visit

Ross Campbell, Ian Jamieson, John McGahey and Martin were given a tour of the Scottish Parliament and sat in on First Minister's question time. Afterwards we had coffee with Cathy Peattie, MSP for Falkirk East, and she was very interested in hearing about the work of the SDWG.

Ian and John in Cathy Peattie's 'pod'



## NOVEMBER 2008

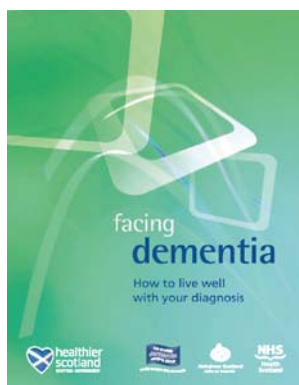
### Work with the Care Commission

Pat McGonigal has continued to be an active member of the Care Commission's Involving People Group. Pat is able to bring his direct experience of living in a Care Home. In addition to this role, Pat has commented on material produced for service users and the new training professional qualification for Care Commission Officers (ROCA). In November, Pat took part in the Group's Development Day in Dundee with an overnight stay in the Apex. He managed to top this in July though with an invitation to attend the Royal Garden Party. As well as seeing the Queen and Prince Philip, Pat also brought the scene to life with a great description of guests holding high heels in one hand, hat in the other to cope with the breeze and very soft grass!



Pat was joined by his colleagues, James McKillop, Edward McLaughlin and Agnes Houston to give two workshops in May at the Care Commission Forum in Glasgow's SECC. The theme of the quartet's presentation was *What does being equal mean for people with dementia?* They discussed active citizenship, a personalised approach to care giving, importance of good communication, respect and dignity and good practice in a care home setting. There were many positive responses from participants. Agnes will be joining Pat on the Involving People Group next year.

### Facing Dementia



The SDWG and Alzheimer Scotland worked in partnership with NHS Health Scotland last year to write a new version of 'Facing Dementia', a booklet which gives comprehensive and useful information for people who have recently had a diagnosis of dementia. The aim is that every person newly diagnosed with dementia receives a copy. Facing Dementia came out in print in December and Health Scotland began the job of distributing

36,000 copies. Members participated at the informal launch on 9 December at the '*What next for Post-Diagnostic Support*' event in Dundee. We were very pleased with the finished product.

## **DECEMBER 2008**

### **Work in Schools**

SDWG is always keen to follow up invitations to speak to school children. Providing an accurate and positive image to children and young people about living with dementia is a powerful way to raise awareness and reduce the negative stereotypes, fear or lack of understanding that may be a first reaction to thinking about dementia. James McKillop visited Jordanhill School in Glasgow twice. At the end of the year he joined a day's debate considering dementia as a policy issue. 6<sup>th</sup> form students were asked to consider increasing numbers of people being affected in coming decades and suggest responses. Students discussed epidemiology, risk reduction and support services. James and two carers joined discussion groups. The students demonstrated a mature understanding and produced some great presentations.

We had wondered whether the day had really given pupils an impression of the personal human experience of living with dementia. James successfully managed to invite himself back to talk to the students the following term to give his own very successful talk. The students had made Alzheimer Scotland their charity of the year. They cited the impact of James's talk as one of the reasons they wished the £19,000 they raised to come to Glasgow to fund a Dementia Advisor. Many thanks Jordanhill pupils, and well done again James.

## **JANUARY 2009**

### **Meeting with the Mental Welfare Commission**

Members met with Donny Lyons, Director of the Mental Welfare Commission Scotland, and Dougie Seath, a MWC practitioner. The MWC is an independent organisation that works to safeguard the rights and welfare of people with a mental disorder, particularly if

they are under a Mental Health Act order or welfare guardianship. However, they will also work with people with dementia not under an order or guardianship. They visit individuals in hospitals and care homes. They are a 'watchdog', but also a 'guide dog', providing help and advice regarding care and treatment. They also carry out investigations, many of which involve either people with dementia or with a learning disability, and issue good practice guidelines for staff.

At the time of the meeting, the Commission were involved in a series of unannounced joint visits with the Care Commission to care homes. In May, 4 SDWG members attended the launch of the final Report from these visits, *I'm Still Me*, which so starkly highlighted the huge journey some care homes need to make to provide better care in terms of mental wellbeing, stimulation and prescription practice.

At our January meeting with Donny, we looked at how we might work together in the future. Donny wants to meet regularly with organisations representing users of mental health services. This provides the MWC with the opportunity to ask if they are doing the right things. Donny suggested that we meet at least annually. Members also agreed to be available to take part in consultations or join working groups.

## **FEBRUARY 2009**

<h3><b>Palliative Care Training</b></h3>
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Edward McLaughlin, Pat McGonigal, Ross Campbell and Agnes Houston have all been involved in providing the closing session of the palliative care training at St Andrew's Hospice in Airdrie. This is a four day course held over four weeks for health care assistants, hosted at the hospice, and led by Sandra White. The course has run seven times during the past year and the feedback from participants has been very positive on each occasion. Sandra said that it was important for us to be the final speakers as it gave the whole course more impact and significance. She described our members as '*stars*'.

## Talks

Members are frequently asked to talk to a very wide range of groups and organisations. This is a sample from the past year:

- Memory group, Coatbridge
- Women's Guild, Wishaw
- U3A Alzheimer's awareness meeting, Edinburgh
- Greenock Dementia café
- Dementia Champions meeting, Dumfries
- Bluebird Care training day, Edinburgh
- Thistle Care Homes, East Kilbride
- Clinical psychologists at Edinburgh University
- Alzheimer Scotland Helensburgh branch AGM

## MARCH 2009

### Alzheimer's Disease International Conference in Singapore

Ross Campbell and Sandra Sutherland attended the Alzheimer's Disease International conference in Singapore at the end of March. Ross said that the conference was brilliant and he had met some fantastic people. Sandra said the conference was excellent and she had met some lovely people from all over the world. Sandra gave a presentation on the "Seize the Day" project in Aberdeen, which created a lot of interest - an account even went into a Trinidad newspaper. Sandra was very pleased to have given the presentation – she said that four years ago she would not have been able to do this, but over time, as she has met others with a diagnosis, her confidence has grown. Congratulations to Sandra.



## Meeting Alex Salmond

Members met with Alex Salmond, Scotland's First Minister, as part of the publicity for Red Nose Day. James McKillop, Pat McGonigal, Agnes Houston and Edward McLaughlin spent an hour talking with the First Minister and he was clearly impressed by what he heard. Following the meeting he wrote saying "*I wanted to take the*



*opportunity to say again how much I enjoyed my visit to learn about the work of the Scottish Dementia Working Group, and to meet some of the people involved in making such a positive impact on improving the quality of life for those with dementia, their carers and families.*" He went on to say that he was keen to explore opportunities for the Scottish government to ensure greater certainty for the future of the SDWG through grant funding once our Comic Relief funding ends in 2011.

## APRIL 2009

### Training DVD

A working group of SDWG members and professional workers was set up to oversee the work on our new training DVD, which is intended to be used as broadly as possible, targeting professionals at all levels within the health and social care sectors. The DVD will be divided into four chapters: the first will show that a good life is possible - looking at people's positive experiences of living with dementia; the second and third chapters will focus on some of the real difficulties experienced by people, looking at both the physical and emotional difficulties, and include tips for coping; and the last chapter will focus on how professionals can help people to realise their potential. Filming is now well underway and it is hoped the working group will view the first approval screening before the end of the year.

**MAY 2009**

## **Alzheimer Europe Conference**



Nancy McAdam, Sheila MacIver, Alzheimer Scotland's Involvement Officer for the Highlands, and Martin Sewell attended the Alzheimer Europe conference in Brussels from 28 – 30 May. It was a very busy conference with a lot of sessions squeezed into the two days.

The quality of presentations was generally very high. Nancy and Sheila gave a presentation on dementia care in the Scottish Highlands, highlighting the challenges for people with dementia in accessing services and for service providers in providing services in rural areas. The presentation was well received. Well done Nancy.



Nancy's local post office

During the conference we had a meeting with members of the Alzheimer Europe Board to talk about how people with dementia can be more involved in the governance of the organisation. We were given a firm commitment that this issue would be resolved by the next conference. Board members also said that they would like to work with the SDWG to develop a 'blueprint' to help campaigning groups develop in other European countries.

## **Meeting with the BMA**

SDWG members met with Dr Dean Marshall from the British Medical Association as the first stage in our campaign to improve the way GP contracts, and in particular the GP review, is applied. Most people with dementia and their carers are unaware of what to expect from the review, which should be carried out every 15 months. We believe there needs to be more information detailing what is required from a review and that there needs to be a more consistent approach from GPs. Dr Marshall listened carefully as members gave their views, but he suggested that in order for GPs to provide a better service to people with dementia, the government needs to provide more funding for GP practices.

## **Glasgow Caledonian University Social Work Department**

James McKillop gave an hour long presentation to a group of social work lecturers at Glasgow Caledonian University. James had been trying to make inroads into the University for several years so this was a landmark occasion. The presentation went very well and clearly made a big impression on his audience. The aim of giving the presentation was as an opening to the SDWG becoming involved in the training of social work students at the university. The presentation was also filmed by Christeen Winford, with the intention of using parts of it in our new training DVD. However, an edited version has also gone to the Dementia Services Development Centre at Stirling University to be included as course material for their Early Interventions and Support Module.

## **South Lanarkshire Sheltered Housing Conference**

Alzheimer Scotland worked in partnership with South Lanarkshire Council housing department to run a staff conference with the focus on dementia. The aim was to support staff who work in sheltered housing to build their skills and understanding of dementia. This was a first for us and we ran two successful workshops with Agnes Houston, Pat McGonigal and Edward McLaughlin taking part in a form of 'speed dating'. Agnes also joined the panel of carers for questions and answers at the close of the conference.

The feedback was very positive: *'The members of the Scottish Dementia Working Group have definitely made an impact and changed staff preconceptions. Those who attended this workshop will not forget their meeting with the SDWG, or the admiration they felt for the group.'*

## JUNE 2009

### **Dementia Awareness Week Conferences**

We were involved in three conferences for Dementia Awareness Week, in Dumbarton, Edinburgh and Greenock. Agnes Houston talked about her own perspectives on the support and information she received following diagnosis. Sadie Bowie had also prepared a talk on her experiences, which was read out at Dumbarton and Edinburgh. This made a great impact. Edward McLaughlin spoke about the SDWG's involvement in producing Facing Dementia. Ross Campbell, James McKillop, Agnes and Edward also led workshops on what group members would want from post-diagnostic services and planning ahead for future services. The feedback was very positive from both the talks and the workshops. The organiser of the Greenock conference wrote to the group saying *'You are very much in demand and I can see why – more power to you and please keep inspiring people with dementia and show them there is a way forward'*.

### **Broadcast on German Public Radio**

Volkart Wildermuth, a journalist from Germany, came to interview four of our members, James, McKillop, Agnes Houston, Pat McGonigal and Edward McLaughlin for a programme about dementia for German public radio. Volkart kindly sent us a recording of the programme; unfortunately none of us can speak German! However, Andrea Kynast, the German social worker who spent a month with the group last year, told us that it was really well made.

## JULY 2009

### Dementia Strategy

In July of this year, the Scottish Government announced that Scotland's first Dementia Strategy is on its way. This is really important as the strategy will shape the future provision of dementia services in Scotland and bring about many of the changes the Scottish Dementia Working Group has campaigned for.

The Dementia Strategy will look to improve:

- early diagnosis and post-diagnostic support
- the quality of care, treatment and support
- the training and knowledge of the workforce

The Strategy should be completed by Easter 2010. We would hope to see some changes in the near future whilst others will be longer term.

Five workstreams have been set up which will take forward the development of the Strategy. They cover:

- 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

SDWG members are represented on each of these workstreams, which puts us in a key position to influence the direction and content of the Strategy. Our wider membership is also being involved through regular bulletins and through a consultation paper issued by the Scottish Government at the end of September. A meeting with Shona Robinson, Minister for Public Health has also been arranged for later in the year to discuss the Strategy.

## AUGUST 2009

### Mental Health Collaborative

Making dementia a priority has given all of us the challenge of learning new terminology in addition to undertaking the work.

The Mental Health Collaborative was set up to support NHS Boards to make the improvements needed to achieve the national improvement targets set by the Scottish Government. For dementia, the HEAT (Health, Efficiency, Assessment and treatment) target aims to improve early diagnosis and also the quality of the health care experience.

The Dementia Reference Group was set up under the Collaborative to work on the dementia HEAT target. The Scottish Dementia Working Group was invited to become a member of this group and through our work three improvement measures were agreed. One of these improvement measures is an audit (a review) of information provided to people with dementia and their carers. It looks at what is provided and asks: does this information meet people's needs? The SDWG was invited to be involved in designing the audit tool.

The working group that was set up to do this proved to be very useful with many opportunities to contribute. We were pleased that our views were taken on board and the audit standard proposed was that:

*'All patients receiving a diagnosis of dementia within the last 15 months should have received a copy of Facing Dementia and information about the Dementia Helpline.'*

If this is approved, all Health Boards will be required to provide this information and we will have taken a step nearer to achieving one of our aims that everyone receives good information and is directed to support at a very early stage.

## SEPTEMBER 2009

### Dementia UK Award for James McKillop



The Dementia UK Awards 2009 were organised by the Dementia Services Development Centre (DSDC). The awards provide an opportunity to celebrate the important work undertaken to support people with dementia in the UK. They are designed to recognise organisations and individuals who have worked to improve the quality of life for people with dementia. The awards were presented as part of the DSDC's 3rd International Conference, Facing the Future, and took place at the conference dinner at York Racecourse on the 15 September. James, who was a founding member of the SDWG and Chairperson until he stood down last year, very deservedly won the award for 'Outstanding Contribution to the Field of Dementia'.

Many congratulations James!