

The Scottish Dementia Working Group
exists to be a voice of people with
dementia

We want to be heard

We support each other

We campaign for better services

We work to change public attitudes
towards people with dementia

We want to see more people with dementia
speaking for themselves

Chairman's report

What a busy year it has been! We may be exhausted by our efforts, but we are kept going by the knowledge that we are making progress. People with dementia in Scotland are now a force to be reckoned with – we most certainly have a voice and it is definitely being heard.

The commitment of the Scottish Government which came to power in May 2007 to make dementia a national priority is a big step forward. We are waiting with interest for an announcement on what this will mean in practice.

A major milestone in the story of SDWG has been the successful establishment of a “North and East” outpost, meeting in Dundee. It has been tremendous to welcome so many new faces into the group. We are still getting to know everyone, but we look forward to seeing members who attend the Dundee meetings becoming active in all the areas of work we get involved in.

The past year has seen some new members of the committee taking on speaking engagements and representing SDWG. This is exactly what should be happening. I would like to thank all the committee, including members who have not been able to continue their involvement – the presence of Cathie Crawford and Isa McFarlane at committee meetings has been missed and our thoughts are with them.

We have benefited from the active participation of our co-opted committee members – Jenny Douglas, Sheena Short and Dot Weaks. My sincere thanks to each of you. Philip Bryers, our National Coordinator, has continued to keep us all on our toes and ensured that we have always got to the right place at the right time.

Finally, we enter 2007-8 with a question mark over our future funding, but we are absolutely certain that whatever the outcome of our funding application, SDWG is here to stay and will continue to go from strength to strength.

James McKillop, Chairman

A year of progress and achievement

**Report on the activities of SDWG in the period 1 October
2006 – 30 September 2007**



OCTOBER 2006

SDWG goes to Berlin

The highlight of the month was the participation of SDWG members, Beatrice Darnell and David Turner in the conference of Alzheimer's Disease International (ADI) in Berlin. David and Beatrice presented a workshop session which included a showing of the newly produced SDWG DVD "*United we stand*". The DVD built on the personal experiences described in our previous DVD, "*Listening to the experts*" by showing what people with dementia have been able to do through collective action. The key messages of the DVD were:

- We have a voice and opinions
- Nothing about us without us
- Living with dementia, not dying of dementia
- Listening to service users can improve services
- Rebuilding self-confidence through campaigning
- Fighting the stigma

Since it was shown in Berlin, "*United we stand*" has been shown at events throughout Scotland, in England and in the Irish Republic and has been commended as a powerful statement of how people with dementia can make their voices heard.

SDWG meets the Minister

SDWG has had regular meetings with Scottish Executive Ministers since 2004, but this year, for the first time, a Minister for Health, Andy Kerr, MSP, came to meet us on our own territory and spent an hour discussing our concerns with us.

We took the opportunity to speak to him about:

- access to medication
- our experience of respite and short breaks
- the special support needs of those diagnosed with dementia before the age of 65
- the importance of early diagnosis and the need for clear pathways of care from day one, and
- financial support for dementia services and for involvement initiatives

Younger people with dementia

Nancy McAdam spoke at a conference at the Dementia Services Development Centre (DSDC), University of Stirling, on her experience as a younger person diagnosed with dementia. As at all conferences at which SDWG members speak, the audience responded warmly to her first-hand account of the condition.



NOVEMBER 2006

SDWG helps to raise awareness

James McKillop and Edward McLaughlin have been working closely throughout the year with Glasgow School of Social Work to ensure that students learn about dementia. Very positive feedback has come from

students, for whom the personal accounts of people with dementia have driven home what it is like to have the condition and to be a service user. In November, SDWG took part in the market place at Strathclyde University for new students entering social work training.

Later in the year, James McKillop was invited to make a presentation to the annual study day for all Mental Health Officers (MHOs) in Scotland. He was able to draw their attention to the importance of seeing a person with dementia over a period to ensure that assessments of capability are not made on the basis of one bad day.

SDWG was represented on the advisory group set up to oversee the production of a DVD, commissioned by the Scottish Executive, explaining the provisions of the Adults with Incapacity (Scotland) Act 2000. Several members were filmed for the DVD, "*Making decisions – your rights*", which is now available free to families seeking information about power of attorney and related subjects.

SDWG ran a workshop about the experiences of our members at a well-attended information day run by Alzheimer Scotland at Ibrox Stadium, Glasgow.

Ross Campbell and Isa McFarlane represented SDWG, and did a presentation, at a conference on younger people with dementia arranged by the Alzheimer's Society in Oxford.

AGM

Our third AGM took place in Dundee, hosted by the Care Commission, whose Chief Executive, Jacquie Roberts, welcomed nearly 50 members and supporters. There were stimulating presentations by Anne Mason (University of Stirling, Highland Campus) and Fiona Smith (NHS Highland) on "*Training your memory*" and by Dr Heather Wilkinson (University of Edinburgh) on "*Hearing the voice of people with dementia – and responding*". Both Anne and Heather provided support when SDWG was first established.



DECEMBER 2006

Building alliances

During December SDWG members took part in the launch conference for VOX (Voices of Experience) VOX is a group representing mental health service users and giving them a voice.

This link took further our partnership working, which, earlier in the year, included opening up a link with Scottish Voices – a group of users and carers involved in social work education across Scotland. James McKillop has continued to play an active role on the committee of Scottish Voices and through this has spoken at a number of conferences for social work trainers.

Another example of our partnership working is attendance by several SDWG members at a “*Having our say*” event run by Shared Care Scotland. This organisation is committed to promoting short breaks and respite provision, and SDWG became a member during the year. Ross Campbell and James McKillop helped to produce a DVD on the importance of respite breaks, and some members attended a major conference on respite and short breaks run by Shared Care Scotland in Dunfermline.



JANUARY 2007

A voice for people with dementia across the UK

James McKillop and Edward McLaughlin have played an active part in planning for a second UK Convention for People with Dementia. SDWG

was a partner in the first Convention held in Newcastle in March 2006 and has continued as a partner, attending planning meetings in Birmingham, Derby and Sheffield during the year in preparation for the second convention in October 2007. This is helping us to network with other campaigning individuals and groups across the UK and to learn about service provision and policy issues south of the border.

Working in partnership with NHS Scotland

Throughout the year Ted Cleland and James McKillop have served on a group, convened by NHS Quality Improvement Scotland (QIS), to produce an integrated care pathway (ICP) for dementia. Through the involvement of SDWG, the voice of people with dementia has influenced the work of the group, whose members are nearly all professionals. QIS has also held involvement meetings for the service user and carer representatives on all five of the ICP groups looking at different mental health conditions.



FEBRUARY 2007

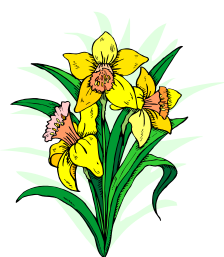
Contributing to Alzheimer Scotland

Two members of SDWG, Ted Cleland and James McKillop, were elected to the Council of Alzheimer Scotland in November 2006. SDWG has played an active part in the work of Alzheimer Scotland in a variety of ways. Ted Cleland serves on the Health and Community Care Committee and James McKillop is on the Staffing Group. Lynda Hogg has become involved in a group which is looking at the information needs of people diagnosed with dementia, and has also been invited to serve on the advisory group for research into unmet need. James McKillop sits on the Dementia Awareness Week planning and review group. SDWG owes a large debt of gratitude to Alzheimer Scotland and has enjoyed an excellent collaborative relationship with it. For a second year, a formal

annual meeting took place between SDWG and the Chief Executive of Alzheimer Scotland.

Dementia is a long-term condition

During the year, the Long-Term Conditions Alliance Scotland (LTCAS) was launched. SDWG members were present at its first major event in the Hilton Hotel, Glasgow. It was a valuable for members to appreciate the similarities between their experiences and those of others with long-term conditions.



MARCH 2007

Dementia Manifesto 2007

2007 was election year in Scotland. Alzheimer Scotland invited all associated groups to contribute to the process of preparing a *Dementia Manifesto* for use with politicians seeking election to the Scottish Parliament and to local councils, and with the new Scottish Government. SDWG met with Alzheimer Scotland's Policy Director, Kate Fearnley, and many of our priorities - including more and better respite - found their way into the *Manifesto*. The key priorities in the *Manifesto* are:

- Making dementia a national priority
- Early diagnosis and support
- Better dementia training
- Making dementia drug treatments available on the NHS
- Free personal care for everyone who needs it
- Raising public awareness
- Funding for research on dementia

SDWG members were proud to be invited by Alzheimer Scotland to present the first copy of the *Manifesto* to the Minister for Health, Andy

Kerr. This was one of many occasions during the year when we featured in the press.

NHS Scotland and access issues

SDWG has worked closely with Fair for All – Disability (initially a part of the Equalities Commission, but working closely with NHS Scotland) We were pleased to be invited to the launch of the report setting out best practice for all parts of the NHS in Scotland.

In the same week Allan Gallagher represented SDWG at a workshop discussing, with staff in the NHS responsible for facilities, how hospitals and other health services premises could be made more “user friendly” for people with special needs.

Principles into Practice

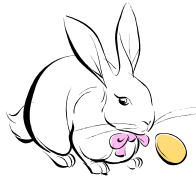
SDWG has maintained an active interest in the work of the Mental Welfare Commission for Scotland and several members attended a lively event at which the principles of recent mental health legislation were debated, with the help of a striking drama presentation by Theatre Nemo. The Mental Health Act 2003 specifies that anyone who is providing care or treatment under law must take into account:

- an individual’s past and present wishes about their care
- the care and treatment that will be of most benefit
- the range of options available for the care and treatment of the individual
- a person’s individual abilities and background
- a person’s age, gender, sexual orientation, religion, racial origin and membership of any ethnic group

SDWG believes that these principles form a sound basis for the care of people at every stage of dementia. The final principle is in line with the equal opportunities policy statement adopted by SDWG in April 2006.

Palliative care

SDWG members are more involved in issues affecting people with mild and moderate dementia than in those surrounding severe dementia, but Nancy McAdam has given a presentation to a conference on palliative care in Inverness. Later in the year, James McKillop also contributed to a conference on this important topic. It links to our concerns about putting advance directives in place so that people with dementia can make known what they would like to happen after they reach the point where they can no longer make decisions for themselves.



APRIL 2007

Citizenship and dementia

James McKillop, Lynda Hogg and Agnes Houston presented a closing plenary session entitled “*We have a voice*” at the first International Conference on dementia at the University of Stirling on 3-4 April 2007 on the theme of “*Citizenship: Responding to the Challenge of Dementia*” The presentation received a standing ovation, and the talks are published in the Journal of Dementia Care, Vol. 15 No. 4 July/August 2007.

“Citizenship for me means being a full member of society, being treated equally and having choices”

Lynda Hogg

I believe I have a lot to give to the community. I believe I have a duty to let the public know that early onset dementia is not the end, but the beginning of a new life”

Agnes Houston



MAY 2007

Collaboration with the General Medical Council (GMC)

SDWG was approached by the General Medical Council (GMC) to advise on a series of GMC/Theatreworks workshops being planned for major cities across the United Kingdom as part of the process to revise a GMC publication “*Seeking patients’ consent – the ethical considerations*”. We met with a producer from Theatreworks to discuss a scenario involving a patient with a diagnosis of dementia requiring a surgical procedure.

SDWG members and people caring for someone with dementia subsequently took part in the workshop held in Glasgow. The Theatreworks presentation of “*Forecast: Fog*” prompted a lively and valuable exchange of views with the good number of doctors present. Some of the doctors, and several SDWG members, stepped into the shoes of the actors to demonstrate “how it should be done”. The event was our best opportunity to date to put our views to a cross-section of medical practitioners.

It also gave us a chance to obtain coverage in a full-page feature by a health correspondent in The Herald on 18 June under the headline “*Putting troubled minds at rest*”.

Alzheimer Europe: Portugal – “What disempowers us – and what can be done”

Edward McLaughlin and Lynda Hogg represented SDWG at the Alzheimer Europe conference in Estoril, Portugal on 9-13 May. The theme of the conference was “*The sound of silence*”. The programme explored how the voice of people with dementia can be heard under the several headings: learning how to listen, amplifying the voice, orchestrating the echo, making the whisper echo, and hearing the sound of silence.

The SDWG contribution took the form of a workshop on “*What disempowers us – and what can be done*”. It used extensive quotes from members about the ways in which they feel disempowered, but also concentrated on their experiences of empowerment. One topic covered was how people were told their diagnosis – in many cases this was far from ideal. Another topic addressed was stigma.

“There is a lot of talk about the stigma of dementia. We believe there is something which can be done about it. By hiding our diagnosis we help to create the stigma. The people creating the stigma are ourselves because we are ashamed of the condition.”

An edited version of the talk has been published and is available from SDWG.

A paper setting out the Scottish experience of respite and short breaks was also presented in Portugal by Edward McLaughlin and Jim Clarke (Alzheimer Scotland)

SDWG has written to Alzheimer Europe emphasising the importance of making it possible for more people with dementia to participate in the next conference in Oslo in 2008, and at subsequent events.

SDWG in the Big Issue

The Big Issue Scotland ran a two-page feature article about Agnes Houston’s experiences - as a carer for her father who has Alzheimer’s Disease, and as someone diagnosed with dementia in her 50s. The poll accompanying the feature asked “*Should the government fund more research into dementia?*” and 96% of the responses said “Yes.” The next issue also contained a letter headed “*Every spare penny should go to Alzheimer’s research*”.

SDWG starts meetings in Dundee

On 24 May, SDWG held its first bi-monthly meeting in Dundee for members from the North East, Tayside and Fife. We had been aware of a growing number of people in these areas interested in SDWG, but the cost of travel, combined with the length of time involved in attending meetings in Glasgow restricted their involvement.

We were overwhelmed to have over 50 people at our first meeting, and more than 30 at our second one in July. The Dundee group is now a lively and important part of SDWG and has doubled our membership.

The generous support of Alzheimer Scotland's branches in Perth and Alyth has enabled us to continue to meet at Discovery Point, which is an attractive and accessible venue in the centre of Dundee.



JUNE 2007

Tackling the stigma: Dementia Awareness Week conference

It is now accepted as routine that people with dementia attend and contribute to Alzheimer Scotland's annual Dementia Awareness Week conference. Over the past few years, lessons have been learned about how to make the event more dementia friendly – including appropriate breaks, shorter presentations, and a mix of content. In 2007 the theme was “*Dementia deserves better – Make dementia a priority in the 21st Century.*”

Agnes Houston spoke about “*Changing attitudes to dementia and tackling stigma*” and four members, together with Chris McGregor, (Vice-convenor of Alzheimer Scotland) presented a final session putting forward a proposed agenda for the new Scottish Parliament.

Working with the Care Commission

Throughout the year, Pat McGonigal has served as a member of the Service Users and Carers Reference Group of the Care Commission. Meetings have been an opportunity to comment on the Care Commission's new approaches to fulfilling its regulation and inspection functions.

SIGN launches dementia guidelines for people with dementia and their carers

In May 2006, Ross Campbell and James McKillop met with two staff from the Scottish Intercollegiate Guidelines Network (SIGN) who were working on a patient version of their national clinical guideline 86: "*Management of patients with dementia*". In June, we were pleased to be represented at the launch, in Aberdeen, of the first batch of SIGN patient guidelines, including one on dementia.



JULY 2007

Being consulted – and consulting

During the year, SDWG has been consulted on a range of matters. These have included:

- A draft shared care protocol for cholinesterase inhibitors in Alzheimer's Dementia (Dr Peter Connelly, NHS Tayside)
- A draft set of dementia diagnosis guidelines on patient and family consultation. (Dr Jennifer Borthwick, NHS Lanarkshire)

- Research on the effectiveness of “talking mats” with people in the later stages of dementia (Cindy Gray and Joan Murphy, Dept of Psychology, University of Stirling for Joseph Rowntree Foundation)
- The development of “Hob Angel” – a kitchen safety device (Cathy Gladwin of Jordan Shaw company)
- Civic Participation Network, for people with communication support needs (Amanda Bennett, Communication Forum Scotland)

In 2006, we established an annual meeting with the Chief Executive of Alzheimer Scotland. This year, we held the first of what we hope will be annual meetings with Prof. June Andrews, Director of the Dementia Services Development Centre (DSDC), University of Stirling. We considered how SDWG and DSDC can work together to their mutual benefit.



AUGUST 2007

Comic Relief and future funding

In August, SDWG submitted its final report to Comic Relief in respect of the three year grant to support the post of National Coordinator which has ended in Autumn 2007. The regular monitoring and evaluation reports submitted over the period 2004-7 have shown a steady advance in the activity of SDWG. We hope we have met the expectations of Comic Relief.

Alzheimer Scotland has ensured that SDWG can continue its work uninterrupted and we are awaiting the outcome of a further bid to Comic Relief. We have submitted a proposal for support from a programme for “*Older people – promoting older people’s advocacy and campaigning*”. A representative of Comic Relief visited us in August to discuss our application and to learn at first hand about our group.

Humour and dementia

Humour plays a big part in our meetings. At one meeting during the year David Turner and Edward McLaughlin proposed that we produce a dementia joke book. Several members attended a workshop at the International Conference in Stirling in which John Killick and Kate Allan talked about “*Stepping into the world of play: humour and people with dementia*”. We contacted them and have planned a workshop with them in October 2007. This will follow up their successful session with SDWG in 2006 on the use of photography and video as a communication tool.

NICE – Outcome of the Judicial Review on medication

Like everyone else, we were dismayed that the Judicial Review into the recommendations of the National Institute for Health and Clinical Excellence (NICE) concluded that the NICE guidance should stand almost unchanged. Our petition of October 2005 to the Scottish Parliament remains open and we are using it to keep the issue alive. We have emphasised that professional judgement should determine whether an individual is prescribed medication for Alzheimer Disease.



SEPTEMBER 2007

Dementia Cafes

A visit to the Fife Cafe in Glenrothes was the latest of our contacts with local dementia cafes, which offer a meeting place and a source of information and support to people with dementia. A number of new cafes have opened in Scotland during the year and we would like to see a network of cafes covering all areas of Scotland. SDWG is a campaigning and awareness-raising group but we know how important services are for

all of us. We believe that cafes offer a point of contact for many people with dementia and their carers from the point of diagnosis.

SDWG goes to Dublin

SDWG was invited to make a presentation to the annual conference of the Alzheimer's Society of Ireland in Dublin. Nancy McAdam gave a personal account of her life since being diagnosed with dementia and also spoke about the work of SDWG and showed "*United we stand*".

General anaesthetics – cause for concern?

Arising from the concerns of some members, and from a feature article and correspondence in the magazine of the Alzheimer's Society, SDWG has begun to gather information about the possible risks associated with the use of general anaesthetics on people with a diagnosis of dementia.

World Alzheimer Day, 2007

This year, World Alzheimer Day coincided with our third meeting in Dundee. We were proud to be invited to host the launch of Alzheimer Scotland's new Schools Pack, and delighted that Shona Robison, MSP, Minister for Public Health, was able to join us. The two winners of a schools poster competition based on Alzheimer Scotland's risk reduction campaign "*Good for you, good for your brain*", presented their framed posters to the Minister.

AND FINALLY!

Meetings

Following our established pattern, the committee has met on six occasions during the year, and five full meetings have taken place in Glasgow, where we have had a variety of speakers. Our AGM was held in Dundee. Additionally, three full meetings for members have taken place in Dundee since May.

Membership

The past year has seen a substantial increase in the number of members on our mailing list. We now send out information about our activities to 67 people with dementia who have attended one or more SDWG meeting, or expressed an interest in being part of SDWG.

Given the increased spread of members, we hope that the newsletter will be published more regularly in future and will become a major link with all our members. We are also looking at how to make fuller use of the internet, through the Alzheimer Scotland site where we have our own page.

Money

A statement of income and expenditure for the period 1 April 2006-31 March 2007 is included in this report. Expenditure in the year was £56,473, compared with £46,092 in 2005-6. This reflects the growing

level of activity, and includes the cost of producing our DVD, “*United we stand*”. Income kept pace with expenditure, with Alzheimer Scotland increasing the level of its support.

A statement of income and expenditure in the 6 month period 1 April -30 September 2007 is also attached. This gives only an approximate picture of our financial position since it covers only a part of the financial year. The additional income of £4,000 to support meetings in Dundee offsets increased expenditure on meetings and roadshows. Following changes in the accounting procedures of Alzheimer Scotland, some additional expenditure headings for support services feature for the first time. The general picture is satisfactory at the end of the first half year.

...and many thanks to all our supporters

SDWG would like to acknowledge its gratitude to all those who have supported us in so many ways during the year, particularly our two main funders - Alzheimer Scotland and Comic Relief.

We wish also to acknowledge the assistance received from Lundbeck Ltd., East Kilbride Kilt Company, and Alzheimer Scotland: Perth and Alyth Branches.

We cannot possibly mention everyone who has given us support during the year. We extend our thanks to you all.

NOVEMBER 2007

ACCOUNTS FOR THE YEAR ENDING 31 MARCH 2007

Income

	<u>£</u>	<u>(2005-6)</u>
Comic Relief	28,953	(29,242)
Other grant income	1,000	(-)
Alzheimer Scotland	25,279	(16,399)
Misc. income	1,241	(452)
TOTAL	<u>56,473</u>	<u>(46,093)</u>

Expenditure

	<u>£</u>	<u>(2005-6)</u>
Staffing		
Salaries	34,801	(29,798)
Travel/expenses	1,130	(1,970)
Training/conferences	521	(265)
Recruitment	-	(-)
Activities		
Meetings/roadshows	6,238	(3,893)
Printing	9,773	(5,637)
Premises		
Rent/rates	2,356	(2,204)
Cleaning	366	(313)
Heating/lighting	152	(407)
Other expenditure		
Equipment	-	(254)
Lease of equipment	9	(-)
Computer costs	158	(149)
Stationery	460	(587)
Postages	297	(281)
Telephone	212	(334)
TOTALS	<u>56,473</u>	<u>(46,092)</u>

**Income and expenditure for 6 months
1 April – 30 September 2007**

INCOME

	<u>Budget</u>	<u>Actual</u>
Grants, etc	7,238	14,695
Donations	-	933
Sale of merchandise	-	112
Alzheimer Scotland branches	-	4,000
Consultancy fee	-	150
Transfer from Alzheimer Scotland	14,000	-
TOTAL INCOME	<u>21,238</u>	<u>19,890</u>

EXPENDITURE

	<u>Budget</u>	<u>Actual</u>
<u>Staffing</u>		
Salaries	16,984	16,500
Travel expenses	1,000	611
Training/conferences	340	90
HR, payroll and training	648	1,295
Recruitment	-	-
<u>Activities</u>		
Meetings/ roadshows	3,750	3,846
Printing	3,750	714
Health and safety	92	184
<u>Premises</u>		
Rent/rates	1,216	1,079
Cleaning	200	177
Heating/ lighting	145	118
<u>Other expenditure</u>		
Office equipment	250	5
IT hardware	500	-
IT support	199	397
Stationery	300	119
Postages	125	58
Telephone/fax	125	112
Insurance	153	305
Finance costs	939	1,878
TOTAL EXPENDITURE	<u>30,716</u>	<u>27,478</u>

