



run by people with dementia

ANNUAL REPORT 2004/5

**This report covers the period 1 April 2004 to 30
September 2005**

Scottish Dementia Working Group

Our aims and objectives

Our constitution commits the Working Group to:

- Being the voice of and for people with dementia nationally and locally
- Influencing public policies that impact on the lives of people with dementia and their families
- Promoting improved provision of services in Scotland
- Developing information, education, awareness and training in the field of dementia
- Reducing the prejudice and stigma attached to dementia

We want to:

**be heard
support each other
get better services
change attitudes to dementia**

INTRODUCTION

The beginnings of the Scottish Dementia Working Group go back to 2002. A steering committee prepared for an inaugural committee meeting on 10 September 2003, at which the Working Group adopted a constitution.

In early 2004, the Working Group secured funding from Comic Relief for a National Coordinator. The post was filled on 1 October 2004. Comic Relief funding for 3 years is being matched by Alzheimer Scotland. The support of both these funders is gratefully acknowledged.

This report covers a period of 18 months, from 1 April 2004 to 30 September 2005.

The committee has met eight times during this period, and there have also been eight full meetings open to all members. We have been successful in involving people from more parts of Scotland and in September 2005, there were 14 members present drawn from nine different local authority areas.

LOCAL GROUPS

Our aim is to develop local groups throughout Scotland. There is a strong Working Group in **Glasgow**, which meets regularly. A recently formed group in **West Dunbartonshire** is active and sends representatives to the Scottish meetings. In the **Falkirk** area, a Mutual Support Group meets monthly and is represented at Scottish meetings. There is now a small group meeting in **Inverness**, and one member has been able to attend some Scottish meetings. In **Edinburgh**, several groups meet, including a monthly Dementia Café. Several people from Edinburgh are active in the Scottish group and a local meeting is planned in Edinburgh for November 2005. The Positive Dementia Group meets in **Aberdeen**, and links have been established through a roadshow visit in September 2005. There is some interest in establishing a group in **Lanarkshire**, and individuals from both North and South Lanarkshire are involved in the Scottish group. Developments in **Lochaber** and **Dumfries and Galloway** are at an early stage. Contacts in **Fife**, **Ayrshire** and **East Dunbartonshire** are being followed up.

“LISTENING TO THE EXPERTS”

In August 2004, 10 members of the Working Group recorded a discussion about their experiences of dementia for a training video funded by Alzheimer Scotland Practice Development Team.

The Deputy Minister for Health and Community Care helped us to launch this as a 30 minute training video, with some notes giving suggestions for trainers, at the Journal of Dementia Care conference in Edinburgh in April 2005.

Since then it has been widely used at training events and has been very well received. We have also shown it to people with a diagnosis of dementia as an introduction to the Working Group. People have commented that it has made them realise they are not alone.

“THE VOICE OF PEOPLE WITH DEMENTIA”

This is the title of our new leaflet introducing the Working Group. We spent a long time planning the content. We wanted it to show people doing ordinary things, to have pictures of older people with children, and to give the message that dementia affects some younger people too.

The leaflet was launched at the Alzheimer Scotland conference during Dementia Awareness Week in June 2005. We are gradually introducing it to clinics and health service resource centres where diagnosis takes place in the hope that it will reach as many people as possible soon after they are diagnosed.

MEETINGS WITH SCOTTISH EXECUTIVE

We were pleased to meet Malcolm Chisholm, MSP, Minister for Health and Community Care on World Alzheimer Day, 21 September 2004, along with carer representatives and Alzheimer Scotland. At this meeting we raised our campaigning issues – early diagnosis, respite provision and access to medication. Our issues have been followed up during the year.

On 20 September 2005, we had another ministerial meeting, with Lewis Macdonald, MSP, Deputy Minister for Health and Community Care. In addition to the issues we had raised at the first meeting we expressed our strong views about the threat to medication for Alzheimer's posed by the NICE recommendations. We also asked for progress on the service proposals set out in the Scottish Executive Health Department Letter of November 2004. We raised the need for more content in professional training about the experience of dementia, and for better staffing in dementia services. The Minister undertook to consider our issues further.

“OVERCOMING THE OBSTACLES”

In November 2004, a Scottish Executive Health Department letter, NHS HDL(2004)44, was issued entitled **“Overcoming the Obstacles to the Improvement of Dementia Care”**. We welcomed its proposals for comprehensive services from the day a person is diagnosed.

Members of the Working Group spoke at three regional seminars, in Glasgow, Edinburgh and Inverness, arranged by Alzheimer Scotland to promote the circular, and some members are now members of planning groups set up in their own areas to implement the template for dementia services recommended by the document.

MEDICATION CAMPAIGN

At the beginning of March 2005, we were stunned by the consultation document issued by the National Institute for Health and Clinical Excellence (NICE). This proposed that the four medications currently prescribed to people with Alzheimer's should cease to be recommended and should not be prescribed to new patients in future.

Quite a few members of the Working Group are prescribed these medications and are convinced that they have been effective in slowing down the onset of the condition, and giving them a better quality of life.

We have had meetings on this issue with the Chairman and Chief Executive of NHS Quality Improvement Scotland (which will make a decision for Scotland when NICE has announced its final decision), and with a cross-party, back bench group of MSPs. We have also presented a

petition to the Scottish Parliament Petitions Committee. Several members have contacted their own MSPs and we have had some press coverage for our views.

We believe that everyone who might benefit from these medications should have the opportunity to try them on prescription and to continue with them as long as they are benefiting them. We accept that they may not be of benefit to everyone with Alzheimer's. We would like to see Memantine (Ebixa) available on prescription in Scotland, and the availability of all these medications extended to people with other forms of dementia where there is evidence that they might be beneficial.

ROADSHOWS

We have attended two roadshows to reach out to people with dementia in new areas. A very successful meeting took place in Fort William, and we had a second successful visit to Aberdeen.

Other visits have taken place to other areas, including Dumfries and Dumbarton. We are planning more roadshows and visits in coming months.

PUBLIC SPEAKING

We have had a very busy year speaking to conferences and meetings. Full details are given in an appendix to this report.

The highlights have been talks to the world conferences of Alzheimer Disease International in Kyoto and Istanbul and to the Alzheimer Europe Conference in Killarney. We believe it is important that people with dementia speak at events like these.

Members have also spoken at conferences in Glasgow, Stirling, Edinburgh, Newcastle and York.

Some members have done presentations to social work and health students. We are keen to do more of this as we see it as very important to influence the attitudes of future professional workers towards people with dementia.

We have also been involved in visiting schools and talking to children in the final year of primary education about dementia. We have had really good responses from the children. This is something else we would like to do more of, if we had enough time.

RESPONDING TO CONSULTATIONS

During the past 18 months we have been asked to comment on a variety of consultations, including the following:

- The Mental Welfare Commission report “Safe to Wander”
- Draft documents from Alzheimer Europe called “After the Diagnosis?”
- Two booklets for people with dementia and carers from the Mental Health Foundation
- Issues involved in animal and stem cell research (Alzheimer Scotland consultation)
- European work on advance directives
- Proposed public information on the Adults with Incapacity (Scotland) Act, 2000
- A leaflet on consent to treatment prepared by Health Rights Information Scotland
- Changes in procedures for registration and inspection used by the Care Commission
- Ideas for Alzheimer Scotland publication on quality of care in care homes
- Feedback on media advertising about dementia for market research group commissioned by Alzheimer Scotland to report on Dementia Awareness Week posters

In addition to all this, our Vice Chairperson has become the first member of the Board of Alzheimer Scotland with a diagnosis of dementia, and our Chairman has played a very active role as a member of the Citizen’s Jury for the 21st Century Review of Social Work in Scotland.

EQUAL OPPORTUNITIES

We do not want to exclude anyone. We realise that for some people, getting involved is harder than for others.

During the year we have had contacts with an organisation for people with hearing impairment, and with someone providing services to older people in the Muslim community.

We realise that a lot of work will be necessary to involve people from communities such as these in our activity, but we are continuing to explore ways of doing so.

OUR VISION FOR 2010

We have drawn up a 10-point vision for 2010, based on the contribution we made to the Dementia North conference in York in April 2005.

OUR VISION FOR 2010

- **Clear pathways for all, starting at diagnosis**
- **Regular reviews as needs change**
- **Local support groups for all**
- **Good networks linking groups of people with dementia to each other**
- **Better services for people in outlying areas**
- **Full information available automatically after diagnosis**
- **Leisure opportunities available to all who want them**
- **Continuing contact, even if someone is not yet ready to get involved**
- **A role in service planning on terms we can understand**
- **Opportunities to influence design features in the places we use**

EVALUATION

The working Group has had a very busy year and has greatly expanded its activities.

More members are gaining the confidence to speak to groups and we are pleased at the increase in invitations we are receiving.

We realise that we will have problems if we try to do too much, and we will have to begin to decide what our priorities are in the coming year if we are not to be swamped by the increasing number of requests for help.

Many of us need a support worker to enable us to take part. Most of us need help using public transport and getting to places. So even if we have the time and energy to do things, we need support staff – and in lots of areas they are not readily available.

The problem getting people from all over the country to Scottish meetings is one reason why we are keen to help local working groups get established. Another reason is that if the national meetings get too big they will be less likely to provide a good forum for people to get to know each other and gain support.

These are challenges for the future arising from our success so far.

Everyone who comes to our meetings gets great strength from meeting other members, and involvement is very good for building self-confidence.

We have made our voice heard on the issues we have chosen to campaign about. We must keep improving our methods of campaigning.

There will always be the need for awareness-raising, and we have ideas about how we can do more of this in the future. People still express surprise that there is a group like ours and that we can make our views known.

We would like to involve more older people with dementia, and to find ways of working with people with dementia who are in care homes.

There is still plenty for us to do!

Scottish Dementia Working Group

ACCOUNTS FOR YEAR ENDING 31 MARCH 2005

Income

| | | |
|----------------------|--|----------------------|
| Comic Relief | | 14,984 |
| Other Trusts | | 500 |
| Alzheimer Scotland | | 13,083 |
| Miscellaneous income | | 57 |
| TOTAL | | <u>28,624</u> |

Expenditure

Staffing

| | | |
|----------------------|--------|--------|
| Salaries | 14,276 | |
| Travel/expenses | 1,394 | |
| Training/conferences | 25 | |
| Recruitment | 5,181 | 20,876 |

Activities

| | | |
|------------------------|-------|-------|
| Meetings and roadshows | 1,724 | |
| Printing | 1,078 | 2,802 |

Premises costs

| | | |
|----------------------|-------|-------|
| Rent and rates | 1,071 | |
| Cleaning | 101 | |
| Heating and lighting | 97 | 1,269 |

Other expenditure

| | | |
|--------------------|-------|-------|
| Equipment | 1,210 | |
| Lease of equipment | 36 | |
| Computer costs | 1,856 | |
| Stationery | 178 | |
| Postages | 134 | |
| Telephone | 264 | 3,678 |

| | | |
|--------------|--|----------------------|
| TOTAL | | <u>28,624</u> |
|--------------|--|----------------------|

Scottish Dementia Working Group

EXPENDITURE, 1 April -30 September 2005

| | <u>Budget</u> | <u>Actual</u> |
|--------------------------|---------------|---------------|
| <u>Staffing</u> | | |
| Salaries | 16,023 | 14,962 |
| Sessional staff | 2,473 | |
| Travel/expenses | 1,000 | 1,529 |
| Training/Conferences | 320 | 160 |
| <u>Activities</u> | | |
| Meetings and roadshows | 3,000 | 1,232 |
| Printing | 3,500 | 3,880 |
| <u>Premises costs</u> | | |
| Rent and rates | 1,000 | 1,148 |
| Cleaning | 127 | 115 |
| Heating and lighting | 127 | 58 |
| <u>Other expenditure</u> | | |
| Equipment | 250 | 34 |
| Computer costs | 500 | |
| Stationery | 250 | 194 |
| Postages | 375 | 105 |
| Telephone | 375 | 207 |
| TOTAL | 29,820 | 23,625 |

MEETINGS

Committee

The Committee met 8 times, on 5 May, 9 July, 7 October, 11 November 2004, 11 February, 14 April, 16 June and 11 August 2005.

Full meetings

There were 8 full meetings during the year:

- | | |
|------------------------|--|
| <u>17 May 2004</u> | Visiting speaker: Dr A Hughes. “Ebixa” Adoption of campaign aims: Early diagnosis, Access to medication, and Respite services (12 members present from Glasgow, Edinburgh, Falkirk) |
| <u>16 August 2004</u> | Visiting Speaker: Janet Woodhouse, Dementia North. Planning for appointment of National Development Officer (7 members present from Glasgow)) |
| <u>7 October 2004</u> | AGM Speaker: Chris McGregor, Vice-Convenor, Alzheimer Scotland (7 members present from Glasgow, Edinburgh, Falkirk)) |
| <u>13 January 2005</u> | Visiting speaker: Alan Jacques, Chairman, Alzheimer Scotland. “Advance Directives” (10 members present from Glasgow, Falkirk, Edinburgh, North Lanarkshire, West Dunbarton, Highland) |
| <u>11 March 2005</u> | Visiting speaker: Gillian Wilson Policy Information Officer, Alzheimer Scotland “Quality of care in care homes”. Consideration of National Institute for Clinical Excellence (NICE) proposals on access to medication for Alzheimer’s on prescription. Jim Jackson, Chief Executive, Alzheimer Scotland present. |

(10 members present from Glasgow, Falkirk, Edinburgh, West Dunbarton, Highland))

12 May 2005

Visiting speakers: Allison Brisbane (Information Asst, Alzheimer Scotland) and Nada Savitch (Alzheimer Society) Using Websites.

(10 members present from Glasgow, Falkirk, Edinburgh, West Dunbarton)

14 July 2005

Speaker: Jenni Campbell on the Scottish Parliament. Discussed use of the word “dementia” raised by Quebec Alzheimer Societies.

(12 members present from Glasgow, East Renfrew, Edinburgh, Falkirk, North Lanarkshire, South Lanarkshire)

8 September 2005

Speakers: Jan Killeen, Scottish Executive on Adults with Incapacity (Scotland) Act, 2000, and Brenda Rattray on a proposed new service development in Aberdeen. Preview of Ross Campbell’s presentation to ADI conference in Istanbul. Planning for meeting with Deputy Minister. Approval of petition on medication to Scottish parliament.

(14 members present from Glasgow, North Lanarkshire, South Lanarkshire, West Dunbarton, Falkirk, Edinburgh, East Renfrew, Aberdeen, Highland)

MEETINGS AND EVENTS ATTENDED

Below is a list of the main events at which the Working Group has made a contribution. It does not include everything in which the Group has been involved during the period.

| | |
|-----------|--|
| April | |
| May | |
| June | Speaker at Dementia Awareness Week conference on “Stimulating Breaks” |
| July | |
| August | |
| September | Speaker at Alzheimer Disease International conference in Kyoto, Japan Meeting with Malcolm Chisholm, Minister for Health and Community Care |
| October | First AGM |
| November | Four members interviewed by market researcher for report on Dementia Awareness Week publicity Three members made presentations to welfare rights officers at Scottish Welfare Rights Forum in Edinburgh Report given to Alzheimer Scotland AGM |
| December | Group members met Depute Minister at opening of Oxford Street premises Presentation to Renfrew Dementia Interest Group for professional staff |

| | |
|----------|--|
| January | <p>Two members gave presentation to students at Glasgow School of Social Work</p> <p>Members visited Edinburgh Dementia Café</p> |
| February | <p>Group represented at Dementia Awareness Week planning group</p> <p>Second presentation to students at Glasgow School of Social Work</p> |
| March | <p>Chairman of Working Group invited to speak at Middle East Alzheimer Conference in Beirut</p> <p>Member of Working Group attended Alzheimer Scotland Council for the first time as a member of this governing body</p> <p>Talk to gerontology group of Health and Well-being in Later Life initiative in Paisley</p> <p>Members made presentations to three seminars (in Glasgow, Edinburgh and Inverness) on Health Department Letter about dementia services</p> |
| April | <p>Meeting with members of Swedish Alzheimer Society in Glasgow</p> <p>Two members of group spoke to Dementia Care conference in Edinburgh. Deputy Minister launched video “Listening to the Experts”</p> <p>Chairman and one other member spoke to Alzheimer Scotland Lanarkshire Region about Working Group</p> <p>Lochaber Roadshow in Fort William. 6 members attended. Around 6 people with dementia from Highland present.</p> <p>Input from SDWG at Stirling University conference on “Joined up services for people with dementia and their carers”</p> <p>Three members of group spoke at Dementia North conference in York</p> |

| | |
|-------------|--|
| <p>May</p> | <p>Visit to The Elm Centre, Dumbarton to meet West Dunbarton group.</p> <p>Contributed to a focus group at Scottish Consumer Council (Health Rights Information Scotland) on consent to examination and treatment</p> <p>Met with Alzheimer Scotland to provide comments on research fellowship bids</p> <p>Represented at Social Work Inspection Agency Partners' Launch</p> <p>Informal meeting with group of people with dementia in Dumfries</p> |
| <p>June</p> | <p>Input to meeting of Passenger Transport Liaison Group</p> <p>Two members presented papers at Alzheimer Europe conference in Killarney</p> <p>8 members attended Dementia Awareness Week conference on care homes. SDWG leaflet launched</p> <p>Member of group profiled in special Scotsman newspaper feature on dementia</p> <p>One member took part in Care Commission Forum on registration and inspection</p> <p>Group described in Sunday Post advertorial placed by Alzheimer Scotland</p> <p>Meeting with representative of Mental Health Foundation to discuss content of forthcoming publication</p> <p>Represented at Health and Wellbeing in Later Life event in Paisley</p> <p>Chairman spoke at Stirling University conference on "Depression, dementia and older people"</p> <p>Member spoke at National Institute for Mental Health in England conference in Newcastle</p> |

| | |
|-----------|--|
| July | <p>Took part in “Campaigning for success” training day in Edinburgh</p> <p>Interviewed on BBC Radio Scotland about dementia</p> <p>Produced comments on stem cell and animal research for Alzheimer Scotland consultation exercise</p> |
| August | <p>Group attended meeting with Chairman and Chief Executive of NHS Quality Improvement Scotland on medication issue</p> <p>Presentation to Parkview Resource Centre, Shettleston on distribution of leaflet to newly diagnosed people</p> |
| September | <p>Prepared response to Care Commission on their consultation document about registration and inspection</p> <p>Visited Glasgow Central Mosque to discuss dementia issues in Muslim community, and possible links</p> <p>Roadshow in Aberdeen. Three members attended and met around 10 people with dementia from Aberdeen and Moray</p> <p>Met Deputy Minister for Health and Community Care at Scottish Executive</p> <p>Represented at meeting of MSPs to form a cross-party dementia group</p> <p>Chairman interviewed by Radio Scotland</p> <p>Spoke at meeting of NHS Lanarkshire Ethics Group</p> <p>Provided training for new Helpline volunteers</p> <p>Assisted researcher from Edinburgh University doing research on dementia</p> <p>Member of group presented a paper at Alzheimer Disease International conference in Istanbul</p> |

CONTACT US

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Photographs

Launch of “Listening to the experts” with Rhona Brankin, MSP. April 2005

Lochaber roadshow. April 2005

Meeting with Lewis Macdonald, MSP, Deputy Minister for health and Community Care. September 2005

World Alzheimer Day, 21 September 2005. Scottish Parliament.

