



run by people with dementia

Scottish Dementia Working Group



Annual Report 2016 – 17



Scottish Dementia Working Group committee meeting
- Glasgow, June 2017

Contents

	Page
Foreword – Jim Pearson	2
Foreword – Chair, Archie Noone	4
Foreword – Vice Chairs	6
Report on Activities:	
Report on activities	8
Diagnosis, Post-Diagnosis and Continuing Support	10
Working in Partnership: Local, National and International	12
Supporting a Well-Trained Workforce	14
Building Capacity of SDWG	16
Committee Members	18
Funding and Support	19

Foreword – Jim Pearson

At the end of another busy year, it is a pleasure to once again look back on the work of the Scottish Dementia Working Group (SDWG). As always, I am continually impressed by both the commitment of individual members and the way in which they come together as a strong collective voice campaigning to improve the lives of people with dementia.

This year has seen the SDWG involved in a huge range of activity related to campaigning priorities of diagnosis and continuing support; working locally, nationally and internationally, building the group's capacity; and supporting a well-trained workforce.

Amongst many other successes, the group this year have launched a new 'Living and Learning with Dementia' film, challenging stereotypes by highlighting the benefits of technology and learning for people with dementia. Elsewhere, members have also spoken at a number of conferences and events to a range of audiences across the dementia workforce and beyond, leaving a lasting impact with attendees who have shaped their practice and attitudes based on the powerful stories of SDWG members.

The SDWG have continued to work successfully in partnership with Alzheimer Scotland and external partners across their priorities. This year Scotland's third National Dementia Strategy was published

after a development process in which members of the SDWG were active participants. The group continue to meet regularly with Scottish Government representatives, posing important questions around the implementation of the strategy and ensuring that the voice of people with dementia is heard strongly across Scotland.

Locally, too, the SDWG has had a strong impact; members from a number of areas took part in Alzheimer Scotland's campaigning around local council elections with the testimony of SDWG members securing the support of many candidates across the country. I have also been pleased to see the SDWG's presence increase in localities, with members travelling regularly this year to build relationships with local engagement groups. This sharing of national and local campaigning priorities will be key to closing the gap between national policy commitments and the lived experience of people with dementia and those who care for them. Strong and meaningful engagement of people with dementia will be crucial as we engage with locally elected representatives and Integration Joint Board officials and ask them how they will ensure delivery of these national commitments at local level.

Under the strong leadership of this year's office-bearers Archie Noone, Carol Hargreaves and Anne

Macdonald, it has been a pleasure to witness the SDWG growing and changing to accommodate a large and diverse membership. A number of new members from across Scotland have become active within the SDWG, with the changed structure of general meetings ensuring that as many voices as possible are heard and can contribute to the group's work. I extend my congratulations to the committee and wider membership for their hard work which has ensured the great success of these changes.

As ever, I am grateful to the Scottish Dementia Working Group for the vital work they continue to do so successfully. I congratulate the SDWG for their many achievements in the past year, and look forward to continuing our work together in the coming year.



A handwritten signature in dark ink, appearing to read 'Jim Pearson', written in a cursive style.

Jim Pearson
Director of Policy
Alzheimer Scotland

Foreword – Chair, Archie Noone

It has been a pleasure for me to be Chair of the Scottish Dementia Working Group in such a busy and exciting year for the group.

This year we streamlined our workplan and came up with four distinct priorities for the group to work on. As a result we have seen our members involved in a wide range of different activities throughout the year, all contributing towards our ultimate aims of improving services and challenging stigma.

Being from Dundee myself, I have been particularly pleased to see the growth of our North East membership this year. Thanks to the hard work of North East Development Officer Wendy Rankin and our members, we have seen a number of new faces getting involved in this area and a regular group has been established, allowing us to engage and campaign locally. Amongst other topics we have looked at the National Dementia Strategy and the provision of post-diagnostic support and link workers locally.

This year's Alzheimer Scotland annual conference during Dementia Awareness Week was also a highlight for the group. I was delighted to open the conference, outlining the importance of research in all the work we do and praising the fact that there were more people with dementia present than ever before. Our Vice-Chair Anne Macdonald also

spoke at the conference, and the Scottish Dementia Working Group stall remained busy throughout the day as attendees came to ask questions about our work. This year, we also had a small film booth at the conference where people could watch some of the clips and films we have produced over the years. The opportunity to have a seat and enjoy the humour of our members was well-received amongst a busy programme!

Scotland's third National Dementia Strategy was also launched this year, after a long period of development which I and various other members of the working group had been involved in. I was delighted to attend the launch in June with Minister for Mental Health Maureen Watt MSP and Alzheimer Scotland Chief Executive Henry Simmons, and pleased to see a strategy which is a well thought-out, well-planned blueprint with which to go forward. In particular, the strategy is good news for our campaigning priorities around post-diagnosis and continuing support: the commitments laid out are ambitious and impressive and the working group will continue to push for them to be implemented fully across Scotland.

Another policy development that I was particularly pleased to see was the adoption of Frank's Law by the Scottish Government. The SDWG

have long supported Amanda Kopel's campaign to see free personal care provided to under-65s in Scotland, highlighting it often in our meetings with the Minister for Mental Health. We are all very pleased about the success of this campaign and look forward to seeing the Scottish Government take it forward.

The group this year have really benefitted from having a full staff team to support us. At the beginning of the year we welcomed back National Development Officer Fiona Gordon from maternity leave and in May, Development Officer for Policy and Engagement Rachael McMurphy also went on maternity leave. Her post is being ably covered by Fiona Kane and we are grateful to both of them and to the rest of the staff team and volunteers for their hard work this year. Our thanks also go to Henry Simmons and Alzheimer Scotland more widely for their support of the group and the close and productive partnership that we continue to enjoy.

All in all, this has been a very busy and exciting year for both the SDWG and the dementia world more

widely. I am very proud of the role we have played in important policy developments, and in building up and growing our own group in order to push forward our priorities. The SDWG remain very well-respected and we continue to be asked to contribute to many diverse events and projects. Thank you to all those who have been involved in our work this year, and I look forward to continuing to work with you in future.



Archie Noone
Chairperson
Scottish Dementia Working Group

Foreword – Vice Chairs

This has been a great year for the Scottish Dementia Working Group in which it really feels like we have come together as a strong and productive group speaking as one voice. We have also welcomed many new members and made lots of changes in order to become more effective and representative, and we are seeing the rewards of this in an engaged and active membership which spans the whole of the country.

Some of my highlights this year have been working with students and professionals as part of our priority to support a well-trained workforce. We have continued to support the Dementia Champions programme at the University of the West of Scotland and always enjoy speaking to the Dementia Champions and answering their questions. The work they do is so important in ensuring people with dementia get the best possible support.

It has also been a busy year for elections. In May we took part in Alzheimer Scotland's campaigning around the local council elections, contacting our candidates and other politicians to ask for their support for Alzheimer Scotland's pledge. We really enjoyed this and were proud that our campaigning efforts gained the support of a number of candidates who went on to be elected as Councillors. We now

look forward to building on these relationships as we see how the Dementia Strategy is implemented locally.

The Scottish Dementia Awards was another high point of this year where lots of SDWG members, both new and established faces, came along to celebrate the great work happening around the country. Some of us had helped to judge the awards and it was a pleasure to attend and see the entries you had discussed come to life. This was also a great chance for our members to get together in a more social setting and celebrate the busy year we have had.

On a personal note, this year has been a busy one for me as it was my first as Scotland's representative on the European Working Group. I have attended meetings in Luxembourg, Brussels and Germany, and presented on the importance of humour at Alzheimer Europe's 2017 conference in Berlin. This was a life-changing experience for me as it made me think a lot about my journey since diagnosis and how important the Scottish Dementia Working Group has been as part of that.

I am proud that we continue to provide so many opportunities to so many members and that we are ensuring the voices of people with dementia are heard across Scotland. Being a part of the Scottish Dementia Working Group is still a

pleasure for me every day and I am excited to see the group continue to go from strength to strength in the coming years.



Carol Hargreaves

Joint Vice Chair

Scottish Dementia Working Group

This year has been a very busy one for me personally, as I moved temporarily to London in January while my house was being renovated. The move was very difficult but I have adapted to the change and have enjoyed travelling up to Glasgow for SDWG work and choosing which projects I would like to be involved with from afar.

I am delighted by the changes that have taken place in the group this year. We have welcomed many new members and watched the very positive impact that involvement in the group has had on them. Our general meetings have also changed in format to include speakers and workshops around particular themes

and as a result we are ensuring that we hear everyone's voices.

Research and the involvement of people with dementia in the work of professionals continues to be very important. I have been interested in new developments and areas of research and I was also pleased to speak at Alzheimer Scotland's Dementia Awareness Week conference on the theme of research and the idea that "hope is my drug". We continue to emphasise the importance of people with dementia being meaningfully involved in research and in shaping information, and have consulted on NHS guidance documents amongst others.

All in all this has been another busy and successful year for the SDWG in which we have continued to have great influence and the ear of the Scottish Government and others. I look forward to seeing this work continue next year.



Anne Macdonald

Joint Vice Chair

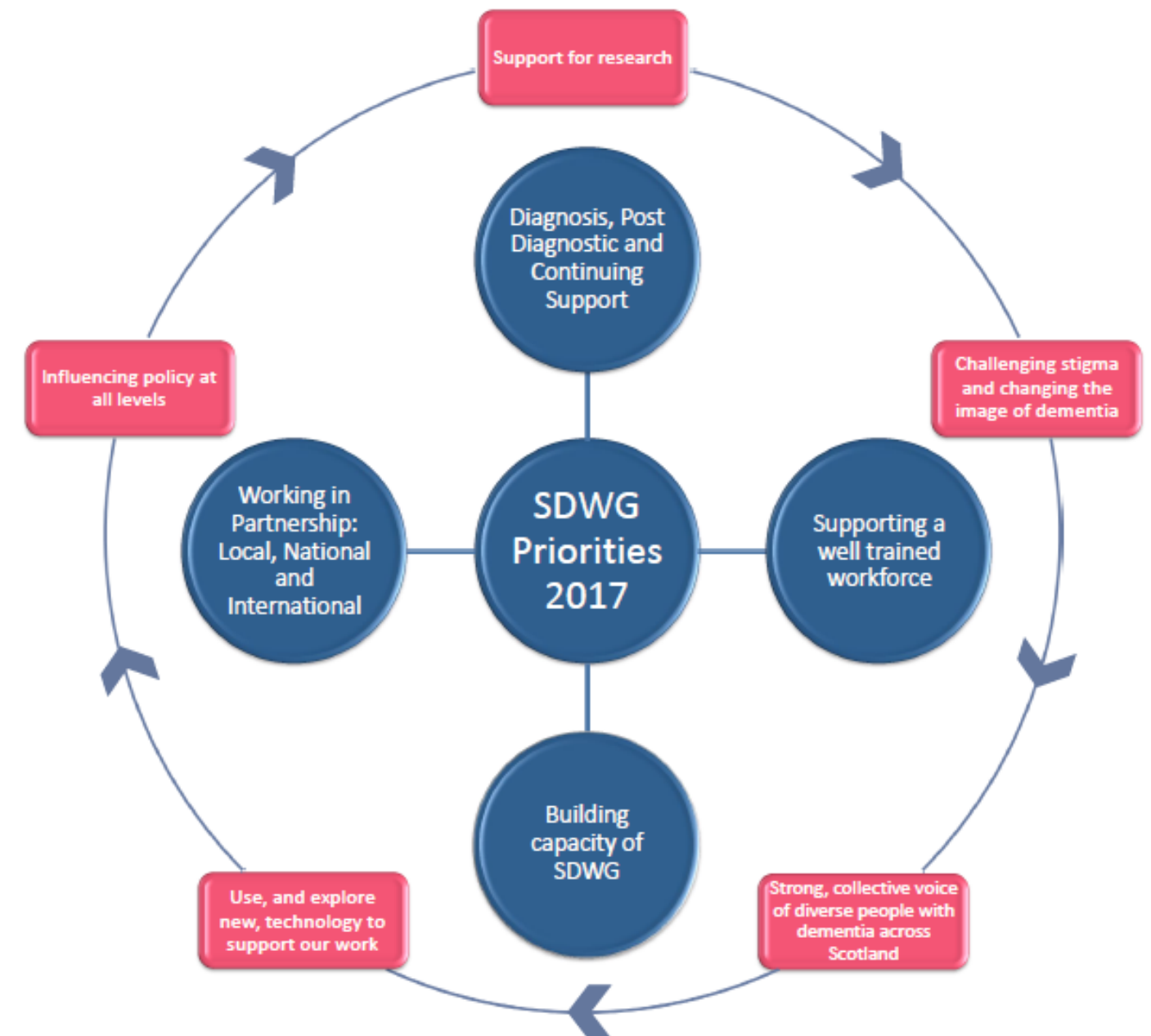
Scottish Dementia Working Group

Scottish Dementia Working Group

Report on the activities of the Scottish Dementia Working Group (SDWG) 1st October 2016 – 30th September 2017

Each year, the SDWG set out their key priorities at a Work Planning Day. This year, the group decided to concentrate on four priorities that all agreed were important for people with dementia. These were: Diagnosis, Post-Diagnosis and Continuing Support; Supporting a Well-Trained Workforce; Building the Capacity of the SDWG; and Working in Partnership: Local, National and International.

Underpinning these are a set of agreed upon 'Key Goals': Influencing policy at all levels; using and exploring new technology to support our work; support for research; challenging stigma and changing the image of dementia; and being a strong collective voice of diverse people with dementia across Scotland. Our commitment to each of these goals is clear in the work we have done towards our priorities.



Diagnosis, Post-Diagnosis and Continuing Support

The experience of being diagnosed with dementia and the support received afterwards has long been a big focus for the group and this year we have campaigned harder than ever around the issue. General meetings in both the West of Scotland and the North East have focused on post-diagnostic support with guest speakers coming along from Alzheimer Scotland's policy team and Focus on Dementia to present on specific aspects of the government's post-diagnostic support commitment.

A number of members have been involved in speaking at local post-diagnostic groups in order to share their experiences and spread the word about the SDWG. Committee members Henry Rankin and Geordie Woods have been involved in this work in Falkirk, while Chair Archie Noone has attended similar events in Perth.

Members have also been involved in a number of conferences and professional events around post-diagnostic and continuing support. In March 2017, SDWG member Ian Symington took part in an event for GPs about the move to providing post-diagnostic support in primary care settings. In the same month office-bearers Carol Hargreaves and Archie Noone attended a ToGeThere event focused on Self-Directed Support (SDS) where they were able to learn more about what this means and hear the experiences of people who have made use of it. Following on from this event, an information session was set up for SDWG members with Alzheimer Scotland's SDS Manager Laura Finnan-Cowan and a session on SDS was included as part of a new training programme delivered to committee members.

As part of campaigning around 'continuing support', we have continued to focus on ways that people with

dementia can remain independent and active, including through housing and assistive technologies. Members therefore visited the Croftspar supported accommodation facility in Glasgow and learned more about assistive technologies when members of Alzheimer Scotland's Technology team presented at general meetings in Glasgow and Dundee.

iPad classes provided by Software Training Scotland also carried on into early 2017 and members have been involved in various pieces of work to show that people with dementia are still able to learn and can benefit greatly from technology. Members have presented at Alzheimer Scotland's 'Confident Conversations About Technology' events and at Scottish Social Services Council annual conference in March and Dementia Caring Congress in April about their experiences of technology.

In May 2017 Henry Rankin, Pat McGonigal and Geordie Woods starred in the film 'Living and Learning with Dementia' which documented their experiences of learning I.T. skills and how this has benefitted them in their daily lives. Henry, Pat and Geordie worked with the Untold Motion Picture Company to plan, record and produce the film together and it has been shown at a wide range of meetings and events. We even enjoyed a premiere at the Oxford Street office when the film was first launched.

We continue to support the use and development of occupational therapy for people with dementia and were pleased to support the publication of the Allied Health Professionals' 'Connecting People, Connecting Support' report in September 2017. SDWG member Pat Barrett spoke at the event about the importance of getting the right support following a dementia diagnosis.



Michelle Miller attends West of Scotland General meeting to talk about post-diagnostic support



Anne, Pat and Carol – Confident Conversations



Living and Learning with Dementia film launch



Pat Barrett speaks at the launch of 'Connecting People, Connecting Support'

Working in Partnership: Local, National and International

We want to make sure that the voices of people with dementia are heard locally, nationally and internationally and we are committed to working in partnership to make this happen.

At a national level, we continue to enjoy a strong and productive relationship with Alzheimer Scotland and Chief Executive Henry Simmons continues to meet with the group four times a year in order to share information and answer questions from group members. SDWG members also contribute to a number of Alzheimer Scotland committees, with Henry Rankin and Peter McLaughlin representing us on the Human Rights and Public Policy Committee and Carol Hargreaves and Nancy McAdam on the International Committee. Office-bearers Archie Noone and Anne Macdonald also regularly attend Alzheimer Scotland's Research Advisory Meetings to discuss and oversee research developments.

We continue to meet with the Scottish Government's Mental Health Minister,

Maureen Watt MSP, twice a year. This year these meetings have mainly concerned Scotland's Third National Dementia Strategy, with members keen to ask about its commitments in more depth, particularly those around post-diagnostic and continuing support. Implementation of the dementia strategy's commitments will largely be a responsibility locally for Integration Joint Boards and we have worked hard to engage at this level too: many of our members took part in campaigning around local council elections in May, lobbying candidates in their area to sign up to Alzheimer Scotland's pledge.

Internationally, we have enjoyed hosting many visitors who have wanted to hear about the SDWG and our work. In January 2017 Vice-Chairs Carol Hargreaves and Anne Macdonald met with two members of the Irish Senate who were interested in finding out more about the group's campaigning, and in summer we welcomed visitors from

Iceland and Denmark respectively, when we shared experiences of services, policy and attitudes towards dementia in our comparative countries. We also enjoyed catching up with representatives from Japan who attended a West of Scotland general meeting following their introduction to the SDWG last year.

For Dementia Awareness Week in June this year we also hosted two Tea and Blether events in Perth and Glasgow. At the latter we welcomed a number of international visitors from Wales, Canada and Australia who also came to the Dementia Awareness Week conference where a number of SDWG members attended and presented. Chair Archie Noone opened the conference and welcomed a record number of people with dementia, while Vice-Chair Anne Macdonald spoke later in the day on the topic of 'Where is my drug?', highlighting the importance of both research and hope for people with dementia.

Alzheimer Europe's annual conference took place in Berlin in October 2017 including a well-received presentation on the SDWG's work with Occupational Therapy interns. Vice-Chair Carol Hargreaves also attended the conference in her capacity as a member of the European Working Group for People with Dementia, giving an excellent presentation on the importance of humour in her life.



SDWG members meet Maureen Watt MSP, Minister for Mental Health



Henry Rankin, Pat McGonigal, Archie Latta and Carol Hargreaves – local election campaign



Glasgow Tea and Blether for Dementia Awareness Week



Vice-Chair Anne Macdonald is filmed at Dementia Awareness Week conference



Example of local elections twitter campaign – Archie Latta

Supporting a well-trained workforce

Supporting a well-trained workforce has remained a key priority for us this year and we have taken part in a number of projects, meetings and events in support of this.

We continue to enjoy a good relationship with NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC). Henry Rankin and Ross Campbell have represented the working group on the NES & SSSC Programme Board this year which oversees staff development and educational activity in the health and social care workforce based on the Scottish Dementia Strategy. Separately members Carol Hargreaves, Pat McGonigal, Henry Rankin and Ian Symington took part in a NES masterclass around technology in November and Henry was joined by Geordie Woods and Peter McLaughlin to present at SSSC's Dementia Ambassadors conference in March, also on the topic of technology. Feedback from staff at these events has shown the impact that hearing from our members has had on them and how they carry out their work with people with dementia.



Intern Beth Crockett with Pat Barrett

We also continue to support the 'Dementia Champions' programme at the University of the West of Scotland by presenting to new cohorts of nursing students who have signed up as Dementia Champions. A number of members have taken part in Dementia Champions events throughout the year, sharing their experiences of living with dementia and the importance of Dementia Champions within the nursing workforce.

Peter McLaughlin, Henry Rankin and Carol Hargreaves also spoke to nurses of the future this year when they joined Dementia Advisor Iain Houston to speak to Access to Nursing Students at West College Scotland, who were pleased to hear from these members about their experiences and be given the opportunity to ask questions about how nurses can best support people with dementia.



Henry Rankin, Carol Hargreaves, Peter McLaughlin at West College

Throughout the year our members have also participated in a number of other conferences and events where they have presented on their experiences to professionals working in the field of dementia. In April, members took part in both Focus on Dementia's annual conference and the Annual Dementia Caring Congress organised by Caring Times and Journal of Dementia Care. Henry Rankin and Carol Hargreaves spoke at Focus on Dementia about their experiences of diagnosis and living well with dementia, while Pat McGonigal and James McKillop joined Carol to attend the Caring Congress where Pat presented about his experiences of iPad classes and embracing technology.

In the summer of 2017 we were once again joined by a team of Occupational Therapy Interns, this time also with an Allied Health Professional volunteer. Beth Crockett, Nicole Kane, Emily Duffy and Lynsey Flannigan worked on a



Geordie Woods, Peter McLaughlin and Henry Rankin – Dementia Ambassadors

'PhotoVoice' project with members Nancy McAdam, Pat Barrett, Josie O'Sullivan, Richard Fairbairns and Tom McGlone in which they documented their daily occupations and the things that are important to them. The members who took part commented on how much everyone involved had gained from this project, with the interns learning more about dementia and our members enjoying the project and tackling stigma in the process.



Barbara Sharp, Henry Rankin, Pat McGonigal – Dementia Champions



Intern Beth Crockett with Nancy McAdam

Building Capacity of SDWG

Lots of very positive changes have taken place in the SDWG this year as we have adapted how we do things and welcomed new members across the country.

General meetings took place in the North East and West of Scotland four times each this year, with an adapted format that saw us focus on one campaigning priority per meeting and combine presentations and speakers with interactive workshops. These changes ensure we are effectively hearing all members' voices and have received very positive feedback from across our membership. Committee meetings continue to take place every two months, and local meetings happen regularly across the country.

We have also welcomed a number of new members across Scotland, making effective use of buddying and new members meetings to ensure people are welcomed properly and given a proper introduction to the SDWG. As a result we have increased our membership across the country and seen capacity grow, particularly in the North East, as more members are able to take part in the wide variety of work we do.

As part of linking up local and national campaigning, we have also enjoyed many visits to local groups in order to hear about their issues at a local level and to share the work we are doing nationally. Many committee members have travelled around Scotland to meet these groups, and we have visited the Inverclyde Dementia Reference Group; Aberdeen Positive Dementia Group; Borders Dementia Working Group and Baristas Dementia Café in Falkirk, as well as hosting regular meetings in Perth.

For the first time this year we introduced a training programme for committee members, who attended four sessions in total across the year. These were delivered by Alzheimer Scotland's Training Department in collaboration with others and covered 'Understanding Dementia'; Dementia and Equalities (with a particular focus on the Lesbian, Gay, Bisexual and Transgender community); and Self-Directed Support. Committee members have commented on how much they have enjoyed these sessions and how useful they have found them, and we look forward to continuing our training programme with 2017/18's committee.



North East General Meeting



New members introductory meeting in the West of Scotland



Living and Learning with Dementia film launch



Visit to Croftspar supported accommodation



Committee at Christmas 2016



'Understanding Dementia' Training Session



Positive Dementia Group – Aberdeen



Dementia and Equalities training



Glasgow General Meeting

Committee Members 2016–2017

Archie Noone	Dundee	Vice Chair
Carol Hargreaves	Glasgow	Vice Chair
Anne Macdonald	East Renfrewshire	Vice Chair
Ross Campbell	Falkirk	
Richard Fairbairns	Argyll and Bute	
Agnes Houston	North Lanarkshire	(resigned June 2017)
Archie Latta	Glasgow	
Nancy McAdam	Highland	
Peter McLaughlin	North Lanarkshire	
Elise O’Hagan	East Dunbartonshire	
Josie O’Sullivan	Glasgow	
Henry Rankin	East renfrewshire	
George Woods	Falkirk	

Co-opted Members

Dr Nick Jenkins

Funding and Support

The Scottish Dementia Working Group is part of Alzheimer Scotland and our income is generated by the Alzheimer Scotland fundraising department and from a three-year Section 10 funded grant from the Scottish Government.

Our annual expenditure in the year 2016–2017 was in the region of £126,231. This is a decrease on the previous year’s expenditure, which was £131,256; this decrease has occurred mostly because of lower meeting costs. Our expenditure covers staff costs; office administration and postage; meeting costs; and the expenses involved for members to attend external meetings, events and conferences.

This financial year the group received around £2,209 in income from grants and donations.

We would like to thank individuals and organisations for their kind donations throughout the year, and to those who provide support for the group through their time and expertise and by assisting members to get to meetings and events. Thank you very much.

