

the scottish
dementia
working group

run by people with dementia

SDWG Members Handbook

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About the Scottish Dementia Working Group



The Scottish Dementia Working Group (SDWG) is a national, member led campaigning and awareness raising group, for people living with a diagnosis of dementia in Scotland. The SDWG was set up in 2001 and has gone from strength to strength since it was established.

We are funded by **Alzheimer Scotland** and the **Scottish Government**, and are the independent voice of people with dementia within Alzheimer Scotland.

We are a friendly and inclusive group led by, and for, people with dementia. We have an elected committee and dedicated members of staff who support the group's activities.

We welcome **anyone** living in Scotland with a diagnosis of dementia. The only requirement for membership is that you would like to meet other people with dementia to discuss things that really matter to you. Although we are not a support group, our members say that they have gained support and made friends through joining the SDWG.

No two people with dementia are the same. We are all different, with different needs



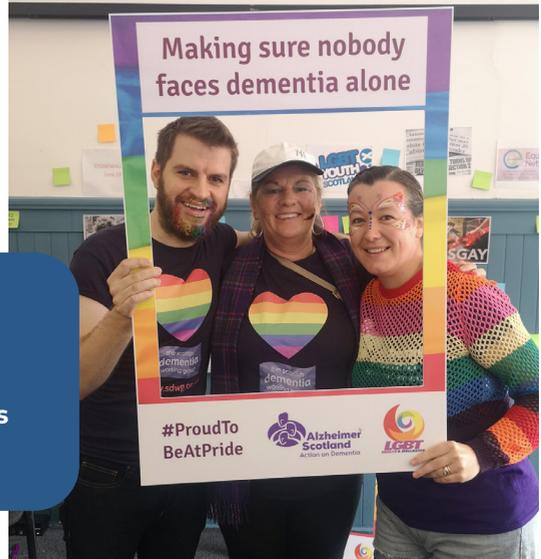
Equality and Diversity Statement



“The Scottish Dementia Working Group members are committed to creating an inclusive and welcoming environment that values diversity. By standing together, we are a stronger, and more powerful voice for people living with a diagnosis of dementia in Scotland today.”

It's important for the group to know about issues with equality and diversity. We need to be able to welcome all new members and make sure the group is representative of all people with a diagnosis of dementia in Scotland

It is important that we engage with, and hear, the voices of people with dementia from all localities within Scotland



SDWG Member Carol at Mardi Gla

Alzheimer Scotland's Aims and Vision



Alzheimer Scotland is the leading dementia charity in Scotland. Alzheimer Scotland campaigns for the rights of people with dementia and their families and provides an extensive range of innovative and personalised support services.

Alzheimer Scotland aims:

- To be the national, and local voice of, and for, people with dementia and their carers in Scotland.
- To improve public policies for the benefit of people with dementia and their carers
- To provide and secure the provision of high-quality services for people with dementia.
- To provide and secure the provision of high-quality services for carers people with dementia.

Alzheimer Scotland vision:

"We aim to engage and connect with everyone who has a stake in what we do; to provide support and information, raise funds, support research, to campaign for and promote the rights of people with dementia and those who care for them.

"Together we can be the leading force for change. Together we can make sure nobody faces dementia alone."

- A human rights approach to policy development
- Involvement of those with lived experience of dementia
- An evidence-based approach
- Partnership working
- A contributing organisation, with a focus on solution

Alzheimer Scotland Board of Trustees

SDWG is part of Alzheimer Scotland and, as such, works within the jurisdiction of Alzheimer Scotland. The Board of Trustees is responsible for the overall governance of Alzheimer Scotland as set out in the Articles of Association, Rules of the Organisation and Trustees Handbook. These include rules which describe the requirement for setting up "groups representing the needs of carers and people with dementia" such as the SDWG

Our Work and Priorities



The remit of the Scottish Dementia Working Group is to:

- Campaign and raise awareness at a national and local level.
- Engage with and inform Scotland's National Dementia Strategies.
- Promote and raise awareness among health, social care and related professions, as well as the wider public.
- To work with all stakeholders at a national and local level, including national and local government, private and voluntary sector providers of health, social care and housing, and other relevant bodies.
- To work with other representative groups, in particular our sister group, the National Dementia Carers Action Network (NDCAN).
- To work with Alzheimer Scotland staff to ensure coordinated and effective campaigning activities.



SDWG Member Henry speaking at Dementia Champions graduation

SDWG members are involved in a wide range of activities. Some examples of what we are involved in include:

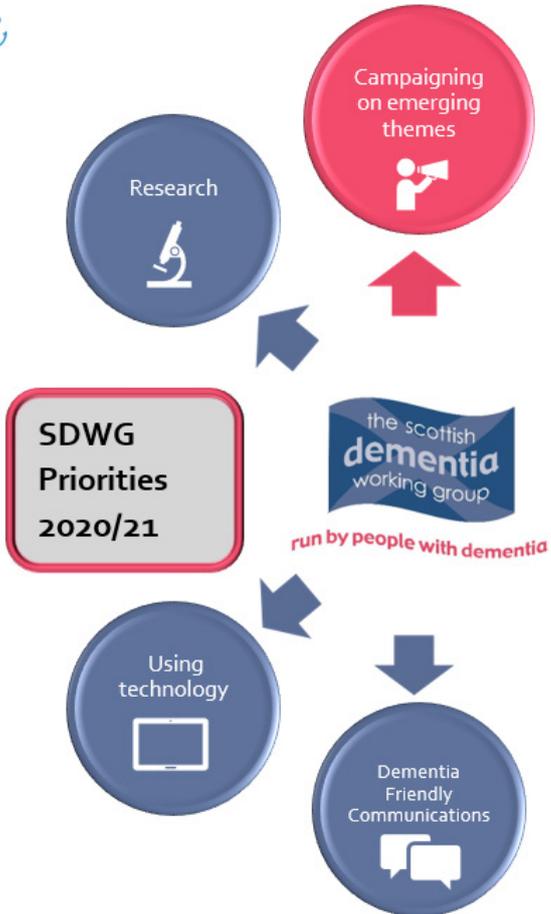
- Meeting with the Minister for Mental Health to talk about key dementia issues and themes
- Attending and presenting at national and international conferences and events
- Local working to hear the voices of those living with dementia throughout Scotland

Each year, the SDWG review the previous year's work and decide on the group's priorities for the coming year. At the beginning of the year, we hold a **Work Planning Day** where the Committee discuss key themes and issues that have come from the wider membership and from local groups. These form the basis for our **priorities** for the year. These priorities will inform the work that the group will undertake over the coming year at a local, national and international level. The SDWG will continuously monitor and evaluate their priorities work and keep their members and stakeholders up to date with the progress through social media, the eNewsletter and the Annual Report. All members will receive a copy of the group's current priorities after they have been finalised.

SDWG Priorities 2020/21

Following on from the priority work done in 2019, as a campaigning group the SDWG will continue **raising awareness**. As we strive to hear the voices of more people with dementia, we will keep making **local connections** wherever and whenever we can. Our commitment to **supporting workforce development** will also be ongoing. For **2020**, we have decided to have **4 priority areas** with a higher priority focus placed on the first area.

1. By capturing themes from Dementia Advisors, Alzheimer Scotland Dementia Helpline and from localities, the SDWG will have a better understanding of what is happening within Scotland. This will help us to focus our **campaigning on emerging themes**. We will establish a process for ensuring these issues are shared with our members. By having this knowledge, members will be in a better position to take work forward and confidently contribute to the discussion. Through working closely with Alzheimer Scotland's communications team, we will **continue raising the SDWG profile** and increase our engagement on social media. We will continue to tell our members stories on our website, highlighting key campaigning issues. We will also continue to explore opportunities with the media that will help to raise the profile of the group.
2. **Research** continues to be an active interest for SDWG especially looking at ways to live well with dementia. Also, of great importance for SDWG is influencing national key research priorities such as prevention, treatment and intervention. Ongoing and active engagement and collaboration with our research partners such as the Scottish Dementia Research Consortium and Join Dementia Research will be crucial.
3. We want to keep our members engaged and connected using the latest developments in **Technology**. Alzheimer Scotland's digital services platform will allow members to reach a much wider target audience in relation to all SDWG campaigning and awareness raising activities. We will also continue to explore and develop social media as a tool to promote all SDWG priorities and to reach out to our supporters and potential new members.
4. We will continue to work closely with Alzheimer Scotland colleagues to produce **dementia friendly communications** that are easily accessible to people living with dementia.



SDWG Structure



Since the Covid pandemic, the SDWG have had to change their way of working. Meetings and all forms of engagement now take place digitally and will do so for the foreseeable future.

Committee

Our Committee meet around six times a year to hear updates on work done by the group, look back at events attended and to review any requests received by the group. The first Committee meeting of the year is also the Work Planning Day where the priorities for the coming year are agreed.

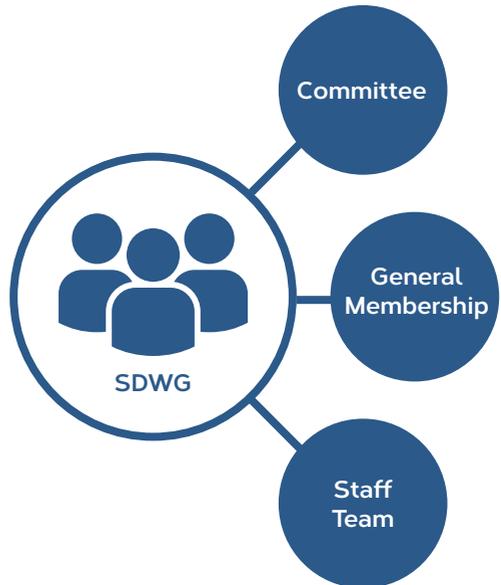
General Membership

Our wider membership is based throughout Scotland. General members are able to attend focus groups, subgroups and get involved in other consultation opportunities. Members are kept up to date on the work of the group through the monthly eNewsletter.

The SDWG Staff Team

We have a staff team who work together to help support members in their engagement. For the moment, the staff team work from home.

The staff team set up and facilitate meetings and events. Staff will also work with members on preparing presentations and speeches for events, going through meeting notes and briefing papers, and making sure that members feel supported and confident in their activities and engagement.



How do I join the SDWG?



SDWG member Danny speaking at a conference

The only requirement that we have for joining the group is that you live in Scotland and have a diagnosis of dementia. We have a membership form that you can fill in and email back to us at SDWG@alzscot.org. Once you have completed the form, a Development Officer will be in touch to talk you through what's involved in being a member and find out what areas of campaigning you are interested in. You will be added to our mailing list and contacted about meetings and opportunities you may be interested in



SDWG member Archie presenting at Alzheimer Europe conference

You can also choose to sign up to receive our monthly eNewsletter (either through email or receive a postal copy). When you become a member of the SDWG there is no obligation to do anything you are not comfortable with. Some of our members are happy just to hear about the work of the group through our newsletter. Other members stand up at events and conferences and talk about their lived experience of dementia. It's up to you how involved you want to be.

Being a Committee Member



We would always recommend that you had been a member of the group for a year before applying to join the Committee. This means that you will have a good background knowledge of the group and the work that we do, and also an understanding of the role of Committee Member. Members are written to at the beginning of each year with an invitation for interested members to apply for Committee. They will be asked to fill in a nomination form stating their reasons for wanting to be on Committee. Existing Committee Members will be asked if they wish to remain on Committee.

What does a Committee Member do?

- Make decisions about running the group
- Review requests that have been received by the group
- Set campaigning work priorities for each year
- Represent the group on different working groups within Alzheimer Scotland, Scottish Government and elsewhere.
- Meet with the Minister for Minister Health, Chief Executive of Alzheimer Scotland and others from key organisations
- Agree AGM and programme for other key events
- Have the option to attend wider variety of conferences and events

How do Committee Meetings differ from other meetings?

They are smaller, and usually without speakers as the agenda has more issues requiring decision and discussion rather than giving information. Work-like but still fun and friendly.

What if I am no longer able to continue as a Committee Member or change my mind?

For all sorts of reasons, sometimes people find they cannot stay on for or need a break and continue again later. Members can resign at any point in the year.

Code of Conduct for Meetings



We believe that all our members and staff should be treated with dignity and respect. Our members created some points to consider for meetings.

- 1.** Any personal issues should be kept out with the meeting
- 2.** Discussions should be relevant to the agenda
- 3.** Transparency in all that we do
- 4.** Patience, respect and empathy for all present.
- 5.** Respect for quieter voices, not everyone is confident about speaking in meetings
- 6.** Any other business – members to update on relevant work
- 7.** Foster an open, non-judgmental attitude
- 8.** Reminder of the role of the SDWG as a campaigning group
- 9.** Importance of confidentiality
- 10.** Conflicts of interest to be declared. Any work being done with other organisations.
- 11.** Abuse of fellow group members or staff will not be tolerated.

Dementia Friendly Meeting guidelines



We try to make our meetings as dementia friendly as we can, this includes:

- Starting meetings mid-morning and finishing mid-afternoon
- Contacting members before meetings to help with any arrangements
- Having breaks in meetings
- Using 'I want to speak' cards
- Keeping presentations short and clear, using 'plain English'

Glossary of Terms



Below are a few terms that you may find in use in SDWG meetings

AHP	Allied Health Professional – support people of all ages in their recovery, helping them to regain movement or mobility, overcome visual problems, improve nutrition, help with communication and restore confidence in everyday living skills, helping them to enjoy a quality of life
DFC	Dementia Friendly Communities – A dementia friendly community is made up of the whole community – shop assistants, public service workers, faith groups, businesses, police, fire and ambulance staff, bus drivers, school pupils, clubs and societies, and community leaders – people who are committed to working together and helping people with dementia to remain a part of their community and not become apart from it.
DLA	Disability Living Allowance – Disability Living Allowance is a tax-free benefit for disabled people who need help with mobility or care costs.
DWP	Department for Work and Pensions – The Department for Work and Pensions is the largest government department in the United Kingdom and is responsible for welfare and pension policy
HIS	Health Improvement Scotland – An organisation which aims to drive improvements that support the highest possible quality of care for the people of Scotland.
IJB	Integration Joint Board – An Integration Joint Board is an organisation which has responsibility for the planning, delivery and resources for Health and Social Care services as delegated by the NHS Board and Local Authority.
PDS	Post Diagnostic Support – The purpose of post diagnostic support is to enable the person with dementia and their family to develop a robust personal plan that will support each person to live well and independently with dementia for as long as possible.
PIP	Personal Independence Payment – Personal Independence Payment (PIP) is extra money to help you with everyday life if you've an illness, disability or mental health condition. You can get it on top of Employment and Support Allowance or other benefits. Your income, savings, and whether you're working or not don't affect your eligibility.
POA	Power of Attorney – A power of attorney is a written authorisation to represent or act on another's behalf in private affairs, business, or some other legal matter.
SDS	Self-Directed Support – Self-directed support allows people to choose how their support is provided and gives them as much control as they want of their individual budget. Put simply, SDS is the support a person purchases or arranges, to meet agreed health and social care outcomes

Contact Us



Address

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Alzheimer Scotland
81 Oxford Street
Glasgow
G5 9EP

Email

sdwg@alzscot.org

Telephone

0141 410 1171

Follow us on Twitter

[@S_D_W_G](https://twitter.com/S_D_W_G)

Useful Links



Alzheimer Scotland website

www.alzscot.org

24 Hour Freephone Dementia Helpline

0808 808 3000

APPENDIX A

Membership Form



run by people with dementia

Basic Information

Please complete the following sections for SDWG records. This information will be stored on the Alzheimer Scotland network, you can ask for it to be removed at any point. Your details will be treated confidentially.

You can ask a family member or friend help you complete the form. SDWG staff can also assist you if required. Please let us know if you require the form in a different format.

Personal Details

Name:

Address:

Telephone Number.:

Mobile Number:

Email address:

Date of Birth:

Use this box to tell us a bit more about yourself

How did you hear about the Scottish Dementia Working Group?

Data Protection

Data protection protects people's rights in relation to how their personal information is used. The Data Protection Act 1998 is the UK law which sets out the requirements of data protection.

SDWG are required to obtain your permission to keep personal information on file. SDWG will not use this information for any other purpose and will always ask your permission before sharing any information with anyone else.

I give permission for the Scottish Dementia Working Group (SDWG) to record and store the information on this form.

✓ or ✗

Name: _____

Signature: _____

Date: _____

Return this form to:

Scottish Dementia Working Group
Alzheimer Scotland
81 Oxford Street
Glasgow
G5 9EP

Tel: 0141 410 1171

E-mail: sdwg@alzscot.org

Web: www.sdwg.org.uk

A member of staff will be in touch with you.

APPENDIX A

SDWG Member Interest Form



run by people with dementia

Member name:

To ensure that we are inviting members to events or meeting that are relevant to their interests, could we please ask you to tick the boxes below to highlight which priorities you are most interested in. There is also a box below which allows you to tell us about any other areas of work you would be interested in taking part in.

Remember, we are a national group so there is no expectation that each member is involved in absolutely every piece of work. Feel free to be involved as much or as little as you like in the groups work!

Priorities you are interested in being involved in:

Equality and Diversity

Research

Transport

Technology

Public speaking and producing scripts

Being involved in filming material (promotional filming)

Policy

Training the workforce

Working with schools

Social Media

Campaigning work within your locality

General SDWG Meetings

Other than these areas, is there any other pieces of work that you would like to be involved in or know about?

Do you feel that you are being given the chance to be involved in SDWG activities/meetings/groups? If no, then please give details