



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 Active Voice team who support the group's activities.

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

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.

**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**

# 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.”**



# 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 of 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.

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

- Meeting with policy and decision makers 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 members discuss key themes and issues. 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.



## Scottish Dementia Working Group Our Priorities 2022

01



### POST DIAGNOSTIC SERVICES

Members' lived experience demonstrates that there is still much to be done to support people living with dementia after diagnosis. The SDWG will continue to campaign for better Post Diagnostic Support (PDS).

### INFLUENCING POLICY & PRACTICE

The SDWG will continue to build and develop its work aimed at raising awareness about dementia and ensuring that people living with dementia have a voice in policies and practices that are important to them.

02



### RESEARCH & BRAIN HEALTH

The SDWG will maintain a keen interest in relevant research developments and engage in appropriate research activities

03



### EQUALITY & DIVERSITY

The SDWG will work to hear from all people living with dementia across the whole of society, including minority groups. It will provide them with an active voice on matters that are important to them.

04



05



### TACKLING STIGMA

The SDWG will challenge stigmatising language and attitudes wherever these are encountered. It will seek to change perceptions and to raise awareness about dementia and people living with dementia where necessary.

# SDWG Structure



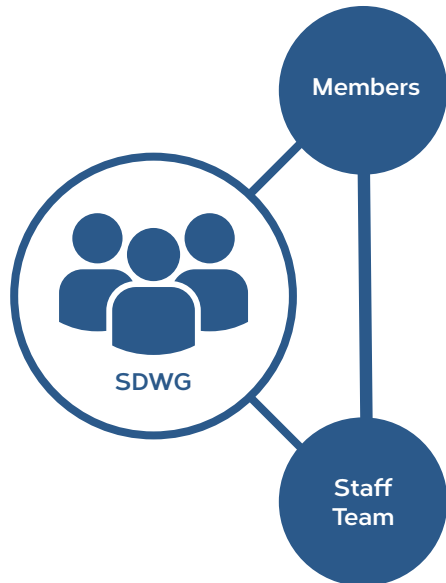
SDWG meetings take place in person and online.

Our members meet regularly 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 meeting of the year is also the Work Planning Day where the priorities for the coming year are agreed.

Our membership is based throughout Scotland. SDWG 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 eNewsletter.



## The Active Voice Team

We have a staff team who work together to help support members in their engagement.

The Active Voice Team set up and facilitate meetings and events. They 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.

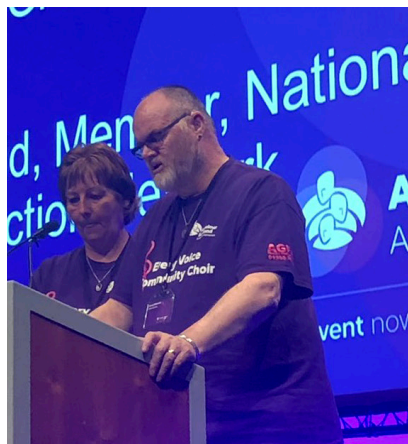
# How do I join the SDWG?



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 [activevoice@alzscot.org](mailto:activevoice@alzscot.org).

Once you have completed the form, an Active Voice 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.



You can also choose to sign up to receive our 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 speak at events and conferences and talk about their lived experience of dementia. It's up to you how involved you want to be.



# 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

<b>AHP</b>	<b>Allied Health Professional</b> – 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
<b>DFC</b>	<b>Dementia Friendly Communities</b> – 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.
<b>DLA</b>	<b>Disability Living Allowance</b> – Disability Living Allowance is a tax-free benefit for disabled people who need help with mobility or care costs.
<b>DWP</b>	<b>Department for Work and Pensions</b> – The Department for Work and Pensions is the largest government department in the United Kingdom and is responsible for welfare and pension policy
<b>HIS</b>	<b>Health Improvement Scotland</b> – An organisation which aims to drive improvements that support the highest possible quality of care for the people of Scotland.
<b>IJB</b>	<b>Integration Joint Board</b> – 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.
<b>PDS</b>	<b>Post Diagnostic Support</b> – 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.
<b>PIP</b>	<b>Personal Independence Payment</b> – 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.
<b>POA</b>	<b>Power of Attorney</b> – 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.
<b>SDS</b>	<b>Self-Directed Support</b> – 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



## Email

[activevoice@alzscot.org](mailto:activevoice@alzscot.org)

**Tel:** 0141 410 1171

## Web

[www.alzscot.org/sdwg](http://www.alzscot.org/sdwg)

## Follow us on Twitter

[@S\\_D\\_W\\_G](https://twitter.com/S_D_W_G)

# Useful Links

## Alzheimer Scotland website

[www.alzscot.org](http://www.alzscot.org)

## 24 Hour Freephone Dementia Helpline

0808 808 3000



# APPENDIX A

## Membership Form



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### 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 to 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 by email to:

activevoice@alzscot.org

A member of staff will be in touch with you.

# APPENDIX A

## SDWG Member Interest Form



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**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 group's 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