

Scottish Dementia Working Group (SDWG)

Members Handbook

activevoice@alzscot.org



Reviewed July 2023

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.

It's important for the group to know about issues with equality, diversity and inclusion. 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.

- SDWG member

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

- SDWG member



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

Scottish Dementia Working Group (SDWG)

Priorities 2023/24



Active Voice - "Enabling and promoting the diverse voices of people with dementia and carers to campaign for, promote and uphold rights and drive change."



Dementia supports & services

Lived experience shows there is still much to be done to support people living with dementia after diagnosis. We will continue to campaign for better dementia supports & service, such as post diagnostic support (PDS)



Brain health

We will promote good brain health & action that can reduce the risk of diseases that can lead to dementia. We will advocate for and support the development of an improved diagnosis pathway, services & supports for people pre-diagnosis



Influencing policy & practice

We will continue to build & develop our work aimed at raising awareness about dementia and ensuring that people living with dementia have a voice in policies & practice

Human rights of people with dementia



Research

We will maintain a keen interest in relevant research development and engage in appropriate research activities



Equality & Diversity

We will work to hear from all people living with dementia across the whole of society, including minority groups, by providing them with an active voice



Tackling stigma

We will tackle stigmatising language and attitudes where these are encountered. We will seek to change perceptions and to raise awareness about dementia and people living with dementia

Dementia Supports and Services

- Campaigning for improved, dedicated Post Diagnostic Support & support pre-diagnosis to meet people's needs
- Advocating for a dedicated Young Onset Dementia pathway & services
- Calling for complete health checks for people living with dementia, at least once a year
- Championing supports and services to meet people's needs throughout their dementia journey



Brain Health

- Supporting the development of a dedicated programme of pre-diagnosis support for people with Mild Cognitive Impairment (MCI)
- Promoting information and advice to help maintain good brain health
- Campaigning for an improved diagnosis pathway with early detection and an early and timely diagnosis



Influencing Policy and Practice

- Influencing & monitoring delivery of national policy & practice, such as the Scottish Government's National Dementia Strategy and National Care Service
- Working with partners to deliver a better deal for people living with dementia, such as through the Fair Dementia Care campaign and the Long-Term Care Commission
- Supporting partners to ensure that service provision and workforce knowledge and practice are informed by people with lived experience
- Building local connections to consult with people affected by dementia from all over Scotland



Research

- Working as partners in research
- Promoting confident conversations in research
- Supporting the commissioning of purposeful research



Equality and Diversity

- Understanding the needs and wishes of people living with dementia across all values, beliefs, communities & traditions
- Reaching people in rural communities
- Promoting confident conversations on equality & diversity
- Hearing from hidden and quieter voices



Tackling Stigma

- Advancing a positive image of dementia
- Working with partners to improve awareness through education and outreach
- Advocating positive and inclusive language
- Promoting members blogs and challenging stigma
- Raising awareness of Young Onset Dementia



About membership

SDWG membership is open to people with dementia throughout Scotland. Members have many opportunities to make a difference to the lives of people living with dementia – from attending regular meetings and events with partners and stakeholders to help influence and shape policy and practice; to supporting research, participating in consultations, and sharing your experiences; and, to receiving regular news, information, and policy updates that can be used to influence dementia policy and practice where you live.

The most important attribute you can bring to SDWG is your personal experience as someone living with a diagnosis of dementia in Scotland. We need members with a wide variety of skills and interests to get involved. We need activist ambassadors, policy influencers and strategists, careful planners, big picture and fine detail thinkers and people who want to make a difference.

Whatever your special interests or particular skills there's a role for everyone and as an SDWG member there is no obligation to do anything you are not comfortable with.

Depending on how involved you would like to be you can choose to be an Active Member or an Associate Member.

Active Membership – if you wish to be actively involved in all aspects of SDWG

- an activist ambassador for SDWG & for Alzheimer Scotland's Active Voice work
- leading, facilitating, and actively participating in events and activities to enable and promote the diverse voices of people with dementia to campaign for, promote and uphold rights and drive change
- regular, active participation in SDWG meetings and events
- sharing your personal experiences, including through consultations, research, campaigning, and communication activities
- receiving all SDWG communications

Associate Membership – if you wish to receive updates and information on the work of SDWG, with opportunities to opt in to participate in activities

- receiving our monthly meeting calendar and regular policy updates & information
- opportunities to opt in to 'all member' meetings and events
- opportunities to share your personal experiences, including participation in consultations, research, campaigning & communication activities

Active Voice staff team

We have a staff team who support members in their engagement, setting up and assisting with meetings and events. Our Active Voice team works 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.

Dementia Friendly Meetings

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'

How to join SDWG

If you live in Scotland and have a diagnosis of dementia you can apply for membership of SDWG. Just complete the membership form, declaration and media permission form at the end of this handbook and return it by email to activevoice@alzscot.org or by post to Active Voice, Alzheimer Scotland, 81 Oxford Street, Glasgow G5 9EP.

On receipt of your completed membership form a member of the Active Voice staff team will be in touch to discuss your application, answer any questions you may have, and chat about any more information we may need to allow us to complete your application for membership.

Following this we will let you know the outcome of your application. Please refer to the What if you encounter a problem? section of this Handbook if you have any concerns regarding the outcome of your application.

What you can expect from us. We aim to make sure you:

- feel welcomed as an SDWG member and have a good understanding of what it does and of Alzheimer Scotland's Active Voice work
- feel supported, safe, and able to participate and engage as an SDWG member
- know what opportunities are open to you
- have the opportunity to give and receive constructive feedback on your experience as an SDWG member
- know who to talk to if you experience any problems or difficulties and have your concerns listened to
- are properly valued and thanked
- are not out of pocket as a result of any reasonable expense incurred whilst undertaking activities as an SDWG member

What we expect from you. We ask you to:

- engage constructively within your chosen role as an SDWG member
- respect confidentiality whenever you are privy to information shared with you in your role as an SDWG member
- be open to giving and receiving constructive feedback on your experience as an SDWG member
- be comfortable seeking and/or accepting support that will assist you as an SDWG member
- extend respect and courtesy to your fellow SDWG members, the Active Voice staff team, partners and stakeholders
- adhere to the Code of Conduct, Equality, Diversity & Inclusion Statement, Social Media guidance and any other policies, procedures and standards referred to within the SDWG handbook

Code of Conduct

This Code of Conduct provides a set of working principles for Scottish Dementia Working Group members.

General

All Scottish Dementia Working Group members are expected to:

- be respectful of and towards the Scottish Dementia Working Group and its members, Alzheimer Scotland and its staff, partners and stakeholders
- be honest, diligent and maintain high standards of dignity in undertaking their duties and responsibilities
- focus their activities as a member on the current SDWG Priorities & Focus Areas
- respect discussions of a confidential nature
- adhere to this Code of Conduct, Equality, Diversity & Inclusion Statement, Social Media guidance and any other policies, procedures and standards referred to within the SDWG handbook

Scottish Dementia Working Group members will not:

- act in any manner that will or could adversely affect the reputation of SDWG and Alzheimer Scotland
- accept any payment from any individual or organisation in relation to any activity that the member is carrying out on behalf of the SDWG
- use their SDWG membership to pursue a personal agenda that is not aligned with the current SDWG Priorities & Focus Areas
- permit any activity which might result in a conflict of interest with SDWG or Alzheimer Scotland, or use any information obtained as an SDWG member for personal or third party gain

SDWG Meetings

Scottish Dementia Working Group members will ensure that:

- conflicts of interest, such as work being done with other relevant organisations, is declared at the start of the meeting, or as soon as is practicable during the meeting
- discussions and contributions are relevant to the agenda
- dignity, patience, respect and empathy is shown to all present
- meetings are held in a non-judgmental attitude with respect shown for those less confident about speaking in meetings
- where possible reference to personal issues is avoided, unless to provide a specific and useful illustration of the matter under discussion
- confidentiality is respected at all times

Conflict of Interest

SDWG members are required to declare all potential interests during meetings as soon as it becomes apparent that any such interest has relevance to the matter under consideration by SDWG. It will then be determined whether the interest is sufficiently substantial to constitute a conflict of interest.

Breach of the Code of Conduct

Where it is believed that an SDWG member has breached the Code of Conduct the situation will ordinarily be discussed informally between the member and Active Voice Lead. The discussion will be noted and, where possible, the situation resolved.

Where the alleged breach is such that an informal discussion is considered not appropriate, or a resolution cannot be achieved informally, it will be necessary to carry out an investigation. Any such investigation will be conducted by a senior manager (the investigating officer).

An investigation may involve interviewing and taking statements. SDWG members will be expected to cooperate fully and promptly with any investigation.

The relevant SDWG member will be advised by the investigating officer of the outcome of the investigation and the proposed action arising from it.

If the relevant SDWG member is dissatisfied with the outcome of the investigation and proposed action arising from it, they may appeal in writing to the Executive Lead People, Wellbeing & Facilities stating the grounds for appeal within two weeks of the date on which the decision was sent or given to them. Receipt of your appeal will be acknowledged within 7 working days.

Breach of the Code of Conduct (continued)

An appeal meeting will be held which will be dealt with impartially by a senior manager who has not been previously involved in the investigation (the appeal officer) and/or the decision under appeal. The appeal officer will conduct such further investigations as necessary before arriving at a decision on the appeal.

The relevant SDWG member will be informed of the outcome of the appeal in writing usually within 20 working days of the appeal meeting. Where it becomes necessary to extend that period, the NDCAN member will be informed and advised of the revised timescale.

The decision of the appeal officer is final and there will be no further right of appeal.

Equality, Diversity & Inclusion

“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.”

To represent people with dementia throughout Scotland, SDWG must:

- act in a manner that, at all times, fosters and embraces a positive and inclusive approach to issues of equality and diversity
- be representative of all people with dementia in Scotland
- be inclusive, and welcome diverse membership

SDWG members will undertake to respect equality and diversity at all times and will ensure that they avoid actions which could lead to direct or indirect discrimination, harassment or victimisation.

Where it is believed that an SDWG member may have breached this Equality, Diversity & Inclusion statement it will be considered a potential breach of the SDWG Code of Conduct and will be considered in terms of the Breach of Code of Conduct provisions accordingly.

Social Media

SDWG recognises that social media is a powerful tool which can bring significant benefits to its work and to Alzheimer Scotland's Active Voice work. It is important, however, that SDWG members who use social media do so in a way which does not compromise the integrity, reputation, or messaging of SDWG or Alzheimer Scotland.

Examples of popular social media sites include, but are not limited to, Facebook, Twitter, LinkedIn, YouTube, Instagram, Snapchat, Flickr, and WhatsApp.

SDWG members are encouraged to utilise their personal social media channels to promote official SDWG and Alzheimer Scotland messages, whilst also ensuring that personal social media channels do not purport to represent SDWG or Alzheimer Scotland, their views, or opinions. Members may wish to include a disclaimer along these lines in social media profiles, however a disclaimer does not waive responsibility for the content posted or interacted with.

SDWG members must always keep in mind that when using a personal social media account every post, comment, like, retweet and share can have either a negative or positive consequence for SDWG and/or Alzheimer Scotland. Every effort must therefore be made to ensure that personal social media activity does not compromise the integrity, reputation, or messaging of SDWG or Alzheimer Scotland.

Where it is believed that an SDWG member may have breached this Social Media guidance it will be considered a potential breach of the SDWG Code of Conduct and will be considered in terms of the Breach of Code of Conduct provisions accordingly.

What if you encounter a problem?

We will try hard to make your SDWG membership enjoyable and worthwhile, but if you encounter a problem we want to ensure you feel able to express your concerns with the confidence of knowing they will be dealt with professionally and appropriately.

Alzheimer Scotland's process for making comments, suggestions or complaints ensures all feedback is treated fairly, impartially and with sensitivity. A copy of our Comments, Suggestions or Complaints leaflet is available upon request.

Glossary of Terms

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

Email

activevoice@alzscot.org

Tel

0141 410 1171

Web

www.alzscot.org/sdwg

Follow us on Twitter

@S_D_W_G

Some useful links

Alzheimer Scotland website

www.alzscot.org

24 hour Freephone Dementia Helpline

0808 808 3000



SDWG membership form

Please complete all the sections on this page, the declaration, and media permission form. All other information is optional. It is very useful to us – but only fill it in if you want to.

Your personal details

Name:

Address:

Email:

Tel:

Mobile:

Please tell us a bit about yourself:

Are you a member of any other similar groups or networks? Please give details

How did you hear about the Scottish Dementia Working Group?

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.

Equality, diversity & inclusion		Research	
Brain health		Tackling stigma	
Public speaking, writing and/or presenting		Being involved in filming	
Training the workforce		Working with schools	
Local campaigning work		Social media	
Transport		Technology	

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

Please complete this section and return this form to activevoice@alzscot.org

I wish to apply for **Active** or **Associate*** membership of the Scottish Dementia Working Group (SDWG). I confirm that I have read the SDWG Handbook and undertake to adhere to the Code of Conduct, Equality, Diversity & Inclusion Statement, Social Media guidance and any other policies, procedures and standards referred to within it.

* Your type of membership can be reviewed/amended in the future to suit your level of involvement

DATA PROTECTION

The Data Protection Act says that we need your permission to keep this information on file. I agree for Alzheimer Scotland to keep this information on its records.
(We will not use it for any purpose other than matters relating to SDWG, and will ask your permission first if we wish to share it with anyone else)

Signature:

Date:

Media Permission Form

To allow us to promote the campaigning and awareness raising work of the Scottish Dementia Working Group (SDWG) and Alzheimer Scotland's Active Voice networks we will wish to obtain media such as photographs, filming and recording of members undertaking activities in their role. To allow us to do this we would be grateful if you could complete the below form.

Should you not wish to provide this permission we will ensure that you are not included in any group photographs, recordings etc.

I give my permission to be photographed/filmed/recorded on behalf of **SDWG/Alzheimer Scotland - Action on Dementia.**

I understand that this media will be used for promoting, publicising or explaining the work of SDWG, Alzheimer Scotland and its partners.

Alzheimer Scotland and its representatives have my permission to edit, reproduce, use, exhibit, display, broadcast and distribute photographs, film and recordings in any media, including social media*.

*If you are uncertain about how photographs, film or audio recordings will be used please ask a member of the Active Voice team.

Photographs, film and audio recordings will be the property of SDWG/Alzheimer Scotland.

SDWG/Alzheimer Scotland will take all steps to ensure photographs, film and audio recordings are used solely for the purposes it is intended for. If you become aware that this footage is being used inappropriately you should inform Alzheimer Scotland immediately.

Before you are photographed/filmed/recorded we need your permission. Please answer question 1 below, then sign and date the form.

Please tick as appropriate:

Do you consent to be photographed/filmed/recorded in your activities as a SDWG member?

☐ Yes ☐ No

Comment if any:

Name of person being photographed/filmed/recorded:

Signature:

Date: