

# National Dementia Carers Action Network (NDCAN)

## Members Handbook

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



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## Who we are

The National Dementia Carers Action Network (NDCAN) is a national campaigning and awareness raising group for carers or former carers of people with dementia. Formed in 2011, NDCAN is an Alzheimer Scotland Active Voice group, which exists to:

**enable and promote the diverse voices of carers and former carers of people with dementia to campaign for, promote and uphold rights and drive change.**

Funded by Alzheimer Scotland and the Scottish Government, NDCAN is an independent voice for dementia carers. We provide a platform and a greater voice to empower those with experience of caring for someone with dementia to influence and inform dementia and carers policy and practice.

NDCAN actively welcomes a diverse membership, and we recognise that dementia carers are individuals with individual circumstances, experiences, culture, and identity, which must inform and sit at the heart of how dementia and carers policy and practice is developed.

Our vision is to ensure:

- that dementia policy and practice in Scotland respects the rights of carers
- that there is an understanding and recognition of the individual circumstances of dementia carers from diverse communities across Scotland
- that person-centred planning underpins the wellbeing of carers throughout the dementia journey

NDCAN members are a friendly and inclusive group, working together to promote and support the rights of carers of people with dementia. We are a member led group, working with partners and stakeholders involved in dementia policy, practice, research, and brain health. Equality, diversity, inclusion & human rights are at the heart of everything we do. Our active members decide on the priorities that NDCAN will focus on, and these are regularly reviewed and refreshed.



If you want to help ensure that the voice of dementia carers across Scotland is heard and help to shape future policy and practice for people living with dementia, their families and carers, the National Dementia Carers Action Network could be for you.

“

It is essential that carers voices are heard as they have such knowledge and experience gained by working at the coalface. Learning from real life experience can help shape and improve standards in numerous areas.

”

- NDCAN member

# Priorities & Focus Areas 2023-24

**ndcan**

National Dementia Carers  
Action Network

## Priorities & Focus Areas 2023-2024

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



### Carer Support & Services

We will campaign at national and local level to ensure people living with dementia and their carers have access to the best possible support and services within their local community.



### Brain Health & Research

We see Brain Health & Research as an interwoven priority which encompasses the need to think ahead to benefit everyone affected by dementia and our future generations



### Influence & Inform Carers Policy & Practice

Our vision is to ensure that dementia policy and practice in Scotland respects the rights of carers, and that policy and practice is meaningfully informed by people with personal caring experience.



### Dementia in Care Homes

We will continue to campaign for positive change to ensure all care home residents who have dementia are provided with the good quality person centred care they deserve.



### Dementia in Hospitals

We will advocate for a person-centred care approach to help alleviate some of the unfamiliar stress and to improve the overall experience and outcomes of hospital care for people with dementia.

Equality & Diversity  
Rights

## Carer Support & Services

We will campaign at national and local level to ensure people living with dementia and their carers have access to the best possible support and services within their local community. This includes the implementation of robust and clear pathways for a timely diagnosis with structured support immediately after diagnosis and throughout the dementia journey. Our work for our Carer Support & Services priority will focus on:

- Continued support for the delivery of high-quality post diagnostic support that is individualised, extends past the one year commitment, and is available not only to those living with dementia, but their carers too.
- Advocating for timely health care checks through your local GP practice. These should be made available annually, at a minimum, and offered to carers as well as those they care for.
- Supporting the implementation of the '8 Pillar Model of Community Support' that sets out an integrated and comprehensive, evidence-based approach to supporting people with dementia living at home during the moderate to severe stages of the illness.
- Supporting the implementation of all elements of the Carers Scotland Act (2016) which aims to better support carers on a more consistent basis so that they can continue to care, if they so wish, in good health and to have a life alongside. This includes the right for all adult carers to be offered an adult carer support plan.
- Seeking proper support to address the financial impact of those caring. For example: carers who have had to give up work or reduced working hours because of their caring role; barriers to receiving Carers Allowance and campaigning for improved rate of Carers Allowance.
- Championing improved carer respite opportunities.
- Helping to ensure carers are recognised as EQUAL partners in care.
- Access to specific carers' counselling for those supporting a person with dementia.



## Brain Health & Research

We see Brain Health & Research as an interwoven priority which encompasses the need to think ahead to benefit everyone affected by dementia and our future generations.

- We will continue to support and promote the work of our colleagues at Brain Health Scotland as they embark on a long-term programme and a shift towards prevention and early diagnosis.
- Through our partnership with the Alzheimer Scotland Centre for Policy & Practice (ASCPP) at the University of West of Scotland (UWS), we will continue to contribute to research and support students both as advisors and co-researchers.
- In addition to maintaining and progressing our collaborative work with the ASCPP we will support other relevant research projects from across a range of disciplines which help deliver research throughout Scotland.
- We will continue to support the development of research ideas and help ensure the research carried out by students is appropriate and makes a meaningful difference.
- We will support 'Join Dementia Research' - a nationwide online and telephone service that makes it easier for people to register their interest in volunteering for dementia research studies. Anyone, with or without dementia, can register their interest in participating in dementia research and be matched to suitable studies.
- We will continue to support the work of the Scottish Dementia Research Consortium (SDRC), in particular the Alzheimer Scotland Student Research Program.



## Influence & Inform Carers Policy & Practice

Our vision is to ensure that dementia policy and practice in Scotland respects the rights of carers, and that policy and practice is meaningfully informed by people with personal caring experience.

Our work over the years has brought about significant progress, however for most people the gap between policy and real-life experience remains too wide.

- We will continue to campaign for a better understanding of the individual circumstances of people living with dementia and their carers across Scotland, and for person-centred planning to underpin the wellbeing of everyone affected by dementia throughout the entire journey.
- We will support the implementation of delivery plans for the 4th National Dementia Strategy. We will campaign to ensure that specific targets, commitments, and funding are laid out in the proposed delivery plans, and we will strive to ensure that carers voices are listened to in every aspect of this work.
- We will campaign for the proposed National Care Service (NCS) to deliver positive transformational change to the approach to social care in Scotland. We will advocate for the voice of carers to influence the delivery of a NCS which best meets the needs of people affected by dementia in Scotland. We will also continue to campaign for action now to improve the lives of those living with dementia or caring for someone with dementia today.
- Participating in the review of mental health and capacity legislation to ensure that any new legislation reflects the needs and experiences of carers of people with dementia.



## Dementia in Care Homes

The COVID-19 pandemic highlighted and magnified long-standing issues with care homes and particularly for those affected by dementia. Evidence has exposed several overarching issues in relation to dementia care in care homes, therefore we will continue to campaign for positive change to ensure all care home residents who have dementia are provided with the good quality person centred care they deserve.

- The pandemic uncovered hugely challenging circumstances around visiting rights for residents and their loved ones, as well as for care home staff and colleagues. To this end, we will continue to support the full implementation of the 'Anne's Law' proposals to ensure that people who live in adult care homes have rights to see and spend time with the people who are important to them.
- We will champion the implementation of the Advanced Dementia Practice Model which sets out an integrated and comprehensive approach to providing care and support for people with advanced dementia and at end of life with dementia.
- We will continue to support Alzheimer Scotland's Fair Dementia Care Campaign which calls for an agreed definition of advanced dementia and seeks to address the inequalities faced by people living with advanced dementia in terms of access to health care, including equality of access to health and nursing care which is free at the point of delivery.
- We will continue to campaign for good practice in line with the National Care Standards which set out what people can expect from care services at all stages of their journey through a service: and the Standards of Care for Dementia which recognises that people with dementia often have great difficulty protecting their own rights.
- We will support workforce development to ensure that all care home staff who are working with people living with dementia, their families and carers have opportunities to achieve the appropriate knowledge and skills in their roles.
- We will support Alzheimer Scotland's Long-Term Care Commission which aims to agree national recommendations for the Scottish Government and other stakeholders to achieve a new, fairer, and more person-centred practice and funding model for the future of long-term care in Scotland.



# Dementia in Hospitals

The unfamiliar environment of a hospital setting can trigger anxiety, confusion, and distress for someone living with dementia, and simultaneously, this has a detrimental impact on their carer.

We will advocate for a person-centred care approach to help alleviate some of the unfamiliar stress and to improve the overall experience and outcomes of hospital care for people with dementia - this includes the admission process, all the way through to a co-ordinated discharge, and ensuring carers are recognised as equal partners and their views are an important part of this process.

- We will continue to raise awareness of the negative impact a hospital admission can have on people affected by dementia, and we will champion positive change.
- We will support workforce development to ensure that all health and social care staff who are working with people living with dementia, their families and carers have opportunities to achieve the appropriate knowledge and skills in their roles.
- We will explore further opportunities to work with teams in acute, community and specialist dementia unit settings to improve hospital care for people with dementia. This includes our on-going collaborative work with Dementia Specialist Nurses and Dementia Champions.
- We will support the 'Transforming Specialist Dementia Hospital Care' report and proposals which seek to improve the experience and quality of support for those individuals requiring specialist dementia care.
- We will support the '10 Dementia Care Actions' created to support the implementation of commitments within the 3rd National Dementia Strategy which is supported by all the NHS territorial boards.
- We will promote the importance of gathering relevant information through the 'Getting to Know Me' form which details the personal history and care needs of a person living with dementia who is admitted to a hospital setting.



## About membership

NDCAN membership is open to carers and former carers of people with dementia throughout Scotland. Members have many opportunities to make a difference to the lives of carers and people 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 and carers policy and practice where you live.

The most important attribute you can bring to NDCAN is your experience of caring for a loved one with dementia. We are also interested to hear from carers (or ex carers) with a wide variety of additional skills and interests to get involved such as activist ambassadors, policy influencers and strategists, careful planners, and passionate carers, 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 NDCAN 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 NDCAN**

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

### **Associate Membership – if you wish to receive updates and information on the work of NDCAN, 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 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 to join NDCAN

If you live in Scotland and are a current or former carer of someone with dementia you can apply for membership of NDCAN. 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](mailto: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 NDCAN 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 NDCAN member
- know what opportunities are open to you
- have the opportunity to give and receive constructive feedback on your experience as an NDCAN 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 NDCAN member

### What we expect from you. We ask you to:

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

# Code of Conduct

This Code of Conduct provides a set of working principles for National Dementia Carers Action Network members.

## General

**All National Dementia Carers Action Network members are expected to:**

- be respectful of and towards the National Dementia Carers Action Network 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 NDCAN 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 NDCAN Handbook

**National Dementia Carers Action Network members will not:**

- act in any manner that will or could adversely affect the reputation of NDCAN 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 NDCAN
- use their NDCAN membership to pursue a personal agenda that is not aligned with the current NDCAN Priorities & Focus Areas
- permit any activity which might result in a conflict of interest with NDCAN or Alzheimer Scotland, or use any information obtained as an NDCAN member for personal or third party gain

## NDCAN meetings

National Dementia Carers Action Network 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-judgemental 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

NDCAN 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 NDCAN. 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 NDCAN 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. NDCAN members will be expected to cooperate fully and promptly with any investigation.

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

If the relevant NDCAN 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.

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 investigation as necessary before arriving at a decision on the appeal.

The relevant NDCAN 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**

NDCAN members are committed to creating an inclusive and welcoming environment that values diversity. By standing together, we are a stronger and a more powerful voice for dementia carers in Scotland today to represent dementia carers throughout Scotland, NDCAN 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 dementia carers in Scotland
- be inclusive, and welcome diverse membership

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

## **Social Media**

NDCAN recognise 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 NDCAN members who use social media do so in a way which does not compromise the integrity, reputation, or messaging of NDCAN or Alzheimer Scotland.

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

NDCAN members are encouraged to utilise their personal social media channels to promote official NDCAN and Alzheimer Scotland messages, whilst also ensuring that personal social media channels do not purport to represent NDCAN 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.

NDCAN 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 NDCAN 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 NDCAN or Alzheimer Scotland.

Where it is believed that an NDCAN member may have breached this Social Media guidance it will be considered a potential breach of the NDCAN 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 NDCAN 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.

## NDCAN 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 your caring role:

Please tell us a bit about your caring role such as your relationship to the person cared for, when they were diagnosed and their condition/type of dementia and any other information you would like to share. This information will help us build a better picture of our membership if you are willing to provide it. It is treated confidentially and will not be shared with other members.

Are you a member of any other Carer Groups or Networks? Please give details.

**Special interests/skills: please tick those applicable**

Listening to carers and representing their wider experiences		Understanding and analysing health and social care	
Supporting other members (including online)		Developing consensus and shared direction	
Public speaking, writing and/or presenting		Reviewing and responding to policy	
Research		Teaching and learning materials and resources	
Post diagnostic support		Better support for carers	
Acute hospitals and care home settings		Advanced dementia and end of life care	

**Do you have any other relevant special interests/skills/knowledge/experience that might support the work of NDCAN?**

**Please complete this section and return this form to [activevoice@alzscot.org](mailto:activevoice@alzscot.org)**

I wish to apply for **Active** or **Associate\*** membership of the National Dementia Carers Action Network (NDCAN). I confirm that I have read the NDCAN 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 NDCAN, 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 National Dementia Carers Action Network 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 **NDCAN/Alzheimer Scotland - Action on Dementia.**

I understand that this media will be used for promoting, publicising or explaining the work of NDCAN, 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 NDCAN/Alzheimer Scotland.

NDCAN/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 an NDCAN member?

Yes       No

Comment if any:

Name of person being photographed/filmed/recorded:

Signature:

Date: