



Alzheimer Scotland
Action on Dementia



ndcan
National Dementia Carers
Action Network

Active Voice
Annual Report 2023

Introduction

Welcome to the Active Voice Annual Report 2023 which takes a look back at Alzheimer Scotland's local and national Active Voice work over the last year and provides a flavour of the work of our two national Active Voice groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN).

We hope this report provides an insight into our campaigning and awareness raising work that helps ensure the voices of people with personal experience of dementia continue to be heard loud and clear.

We would like to thank everyone who has supported our work throughout 2023 – from people living with dementia who have shared their personal experiences with us, to our many partners working in dementia research, care, policy, and practice. We couldn't achieve what we do without your help and support.

We hope you find this report inspiring, interesting and informative. Whether it's campaigning to improve dementia supports and services, influencing dementia policy and practice, or informing dementia research, SDWG and NDCAN members will be that 'active voice', and we look forward to continuing our work in 2024 and beyond.

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Foreword

Henry Simmons, Chief Executive Alzheimer Scotland

I am delighted to be writing this introduction to the Active Voice Annual Report 2023. At Alzheimer Scotland, the voice of people living with dementia and carers is at the heart of everything that we do. Since both groups were formed – the Scottish Dementia Working Group in 2001 and the National Dementia Carers Action Network in 2011, I have watched them go from strength to strength. Over the years, members of both groups have worked tirelessly to raise awareness and campaign to improve the lives of people with dementia, their carers and families, and their hard work and commitment is to be commended.

When I take a look back at some of the fantastic work that SDWG and NDCAN have been involved with over the last 12 months, I am truly inspired. They have accomplished so much in a single year, from sharing their personal experiences at national and international conferences to helping the next generation of health and social care professionals have a better understanding



of what it is like to live with dementia. Active Voice members have also been involved in influencing policy that directly impacts not only their lives, but the lives of future generations – from consultations on the proposed National Care Service to providing feedback on the fourth National Dementia Strategy. Their collective voice is invaluable, and it is vital that decision makers are both hearing and listening to their voices.

I would like to take this opportunity to congratulate all the Active Voice group members for their achievements over the last year and thank them for their contributions. Thank you also to the Active Voice staff team for all the work they do to support members and facilitate their contribution. I very much look forward to seeing what 2024 brings for Active Voice.

Henry Simmons

Henry Simmons



Introductions from Active Voice members

SDWG members

– Stuart Dougall & Kenny Moffat

Our members have had an eventful year, engaging at local, national, and international levels. At a local and national level, we have been actively involved engaging at events such as dementia cafes, attending events and conferences to share our experiences, assisting in campaigns and research, fundraising, working with professional bodies and hopefully going some way to influence and make changes for the future by having our voice heard. On an international level, we had three members represent the group at the 33rd Annual Conference of Alzheimer Europe which was held in Helsinki (Finland) in October 2023.

This last year has brought about significant progress and advances in research. Our members recognise the importance of how crucial this is for a cure, improvement in treatments and care and ultimately hopefully prevention for future generations, with many members taking part in many research programmes and trials.

As a group, we hope you find this report an interesting and informative read, finding out about some of the work that we, as a group, are actively involved in. We finally would like to thank everyone within Alzheimer Scotland, with a special mention to the Active Voice Team for their continued support.



NDCAN members

– Thea Laurie & Joanna Boddy

NDCAN members have been involved in a diverse range of events and activities, always motivated by our aim to support the carers of people living with dementia. The last year has been busier than ever as members focus on the current priorities around brain health and research, dementia in care homes and hospitals – always trying to influence and inform policy and practice from the carer's perspective.

Alzheimer Scotland has the bold strategy of Prevent, Care and Cure and the lived experience and voices of NDCAN are a vital part of the organisation, tackling the issues that we know carers face daily.

We hope you enjoy this report which demonstrates the type of campaigning our members have immersed themselves in over the last year. Whether locally or more globally, whether at conferences or in care settings, whether engaging with MSPs or AHPs or fellow carers, NDCAN try hard to make that difference so that we have a Scotland, where no one will face dementia alone.

We are always grateful for the support from the Active Voice Team, part of the powerhouse that is Alzheimer Scotland. If what you read here in the Annual Report appeals to you, do think about joining us.

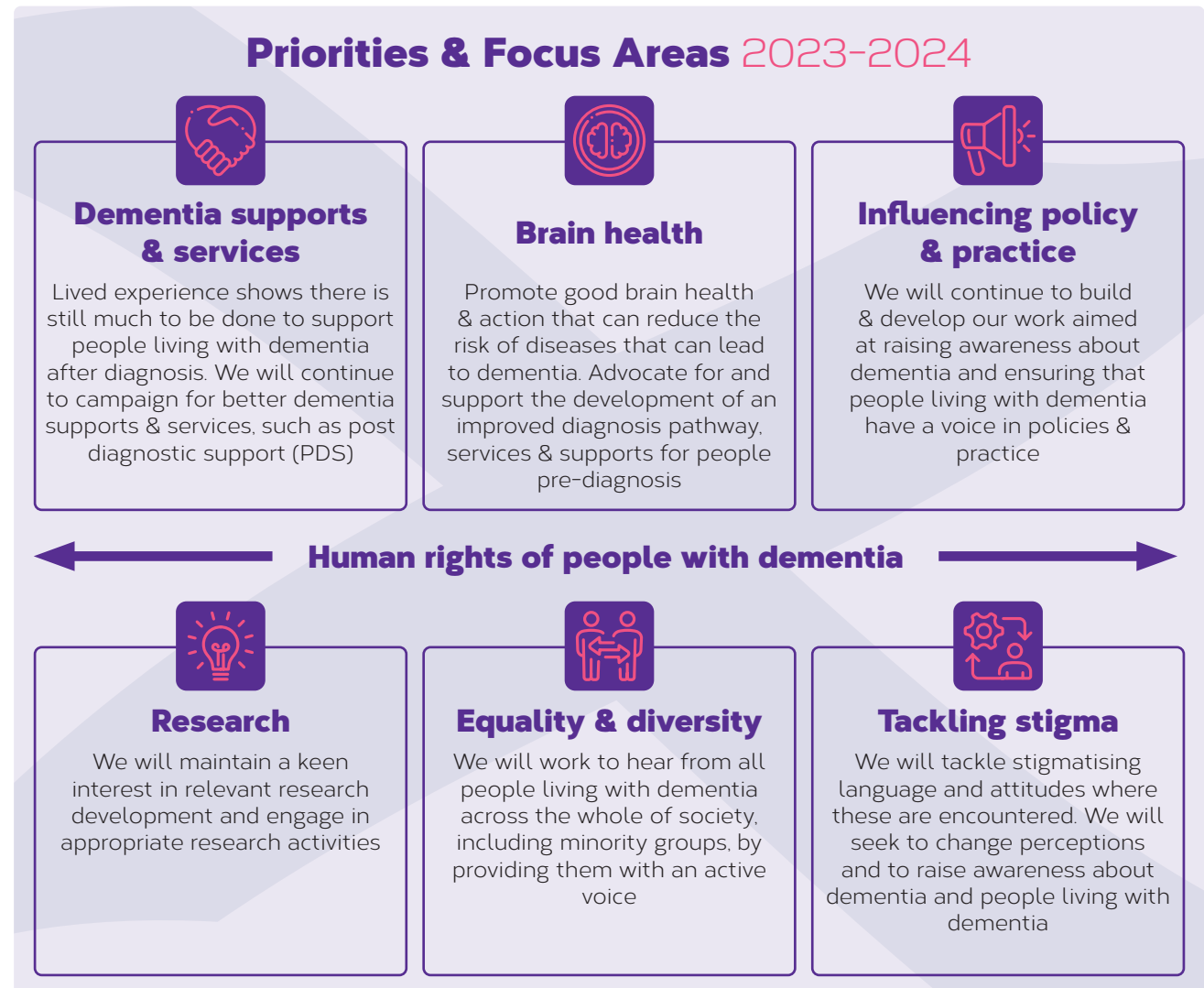


About the Scottish Dementia Working Group (SDWG)



The SDWG is a national, member led campaigning and awareness raising group for people living with a diagnosis of dementia in Scotland. Founded in 2001, the group has been at the forefront of campaigning for improved dementia supports and services ever since, raising awareness to help tackle stigma, working with decision makers to ensure that people living with dementia have a voice to influence policy and practice, and working as partners in dementia research.

For more than 20 years, SDWG members have called upon personal experiences to help make things better for future generations across Scotland and more widely through international engagement with Alzheimer Europe and Alzheimer's Disease International.





Elaine

Thea

Joanna

10
Alzheimer Scotland Centre for Policy and Practice
would like to recognise
National Dementia Carers Action Network
With an Inspiring People Award
For their contributions to the work of the Centre over the last 10 years.

About the National Dementia Carers Action Network (NDCAN)

NDCAN is a national, member led campaigning and awareness raising group of current and former dementia carers in Scotland. Formed in 2011, the group exists to make the voices of dementia carers heard and to raise awareness of the issues impacting on carers.

Since its establishment, the group has campaigned for better carer supports and services, advocated for a person-centred care approach for people living with dementia and their carers, sought to ensure that dementia policy and practice is meaningfully informed by people with personal caring experience; and contributed to the development of dementia research that makes a meaningful difference.

Both the SDWG and NDCAN priorities and focus areas are set by the members, informed by their own personal experiences and by the experiences that they hear about through their engagement with people living with dementia, families, and carers across Scotland. The groups are supported in their work by the Alzheimer Scotland Active Voice staff team who aim to ensure that members feel supported and confident in all aspects of their engagement. Find out more about the SDWG and NDCAN at www.alzscot.org/active-voice



What is Active Voice?

The collective voice of people with lived experience, both those who are living with dementia and carers, is at the heart of Alzheimer Scotland's work. Our active voice network comprises three distinct elements:

- Scottish Dementia Working Group (SDWG)
- National Dementia Carers Action Network (NDCAN)
- Local Active Voice Network

Our two national Active Voice groups, SDWG and NDCAN are made up of people with a diagnosis of dementia and carers, or former carers, of people with dementia. They represent a strong collective voice of people with lived experience across Scotland. The groups campaign for the rights of people with dementia and carers and are committed to ensuring that these principles are upheld so that every person has choice and control, as well as the right to self-determination, inclusion, and equality. They also seek to influence policy and practice at all levels, support research, and raise awareness to challenge stigma and change the image of dementia.

A key focus of the work of SDWG and NDCAN is to gather information from a wider range of lived experiences. This enables the groups to collectively deliver an effective movement of active and diverse voices that represent communities up and down the country.

Localities are therefore at the forefront of our local active voice work. By connecting with people who are living with dementia, their families and carers, hearing what is important to them and building connections, colleagues based in our localities can ensure that the voices of people affected by dementia are heard. The Active Voice staff team is here to support and promote this work, and to ensure that details from everyday conversations are captured, for which a special toolkit has been designed. This ensures an effective mechanism for important information to be consistently recorded.



Active Voice

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

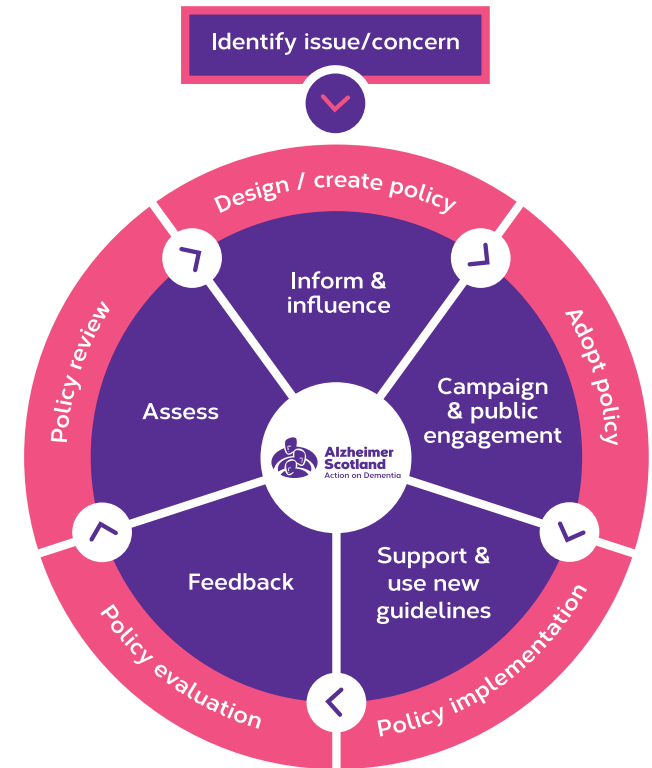
The Active Voice Team

The Active Voice Team is a core component of Alzheimer Scotland's Communications & Campaigns function. This ensures that the voices of people with dementia and their carers inform and shape the organisation's overall messaging and campaign strategies.

Working closely with colleagues across Alzheimer Scotland, we help to make sure that the personal experiences of people affected by dementia drive everything we do as an organisation.

It is important that we remain aware of the current issues and recurring concerns that people with dementia, their families, and carers face daily. This awareness enables SDWG and NDCAN to identify their campaigning priorities, work plans and research engagement. That's why we work particularly closely with colleagues who support people in communities across Scotland, and with our National Dementia Advisor Service.

Only by enabling and promoting the diverse voices of people with dementia and carers can we ensure that the campaigning and awareness raising work of our national and local active voice networks is driving the change in policy and practice that people affected by dementia need. Our Active Voice Toolkit has been designed with that in mind.



- Policy process
- How to get involved with the policy process



Have your say – Local engagement

A key focus of the work of the SDWG and NDCAN is to encourage a wider range of personal experiences to be heard from a broader cross-section of people living with dementia in order to inform our campaigning and awareness raising. Central to that is hearing from those who use Alzheimer Scotland's local Brain Health & Dementia Resource Centres (BHDRCs) and those who are supported by Alzheimer Scotland staff in their local area. Throughout 2023, our members got out and about across Scotland, meeting with and chatting to people about their everyday experiences of living with dementia.

Coffee & Catch-Up

In May, we joined a weekly 'Coffee Catch-Up' group in Alzheimer Scotland's Kilmarnock Centre. SDWG and NDCAN members, Stuart Dougall and Joanna Boddy, chatted about our Active Voice work, their own lived experience, and what membership of the SDWG and NDCAN means to them. The event provided a great opportunity to chat to over 40 people living with dementia and carers, to hear about what's important to them, what works for them and what's problematic in their lives. The session started with a right good singalong and ended with a coffee and networking with those in attendance, providing valuable insights to inform our work.

V&A Dementia Café

Alzheimer Scotland colleagues in our Dundee Centre have a strong partnership with the V&A Museum in the city who host a popular monthly dementia café. This provides an informal and relaxed space for people living with dementia to socialise, unwind, and find out about the services and supports available from Alzheimer Scotland. NDCAN member Marion Ritchie and SDWG members Margaret McCallion and Stuart Dougall joined almost 40 attendees from in and around Dundee at the café in September, and took the opportunity to chat about our Active Voice work, to listen to people's personal experiences, and to find out about the issues that matter most to them.



Hearing from carers

An NDCAN priority is to campaign for those living with dementia and their carers to have access to the best possible services within their local area. We know that whilst some people have good experiences, too many do not.

NDCAN members welcomed the opportunity to meet with three of Alzheimer Scotland's Carer Support Groups during 2023, hearing from dozens of carers from across Aberdeenshire and Argyll & Bute. At these meetings we heard about a wide range of issues, including peoples' pre and post diagnostic support experiences, and the challenges they faced when trying to secure home care, respite, and many other services. Hearing these everyday experiences informs our campaigning priorities and ensures that when we meet with those responsible for delivering services locally and nationally, we can speak on behalf of and represent the experiences of the wider dementia community. We hope to build on this engagement with carers in 2024.





Local consultations

A public engagement event on Alzheimer Scotland's Commission on the Future of Long Term Care took NDCAN members Maureen Huggins and Joanna Boddy, and the SDWG's Stuart Dougall to Alzheimer Scotland's Kilmarnock Centre later in the year. They heard from over 30 people living with dementia who took the opportunity to have their say on this important issue.

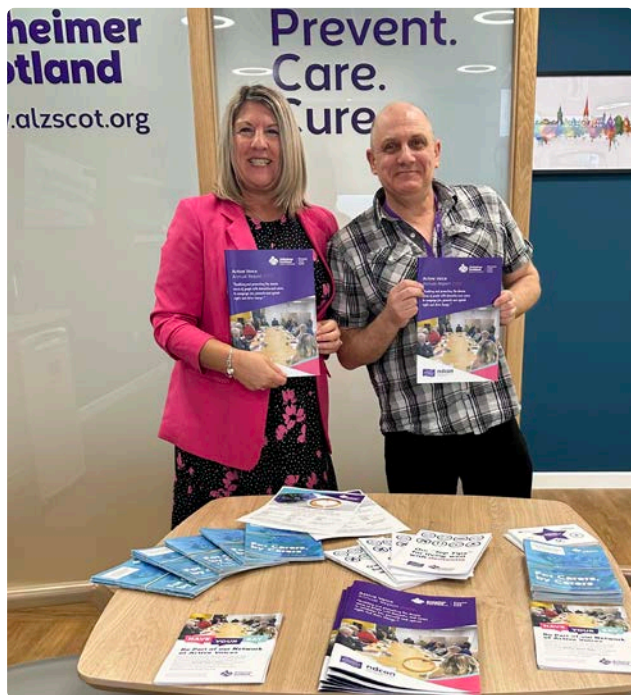
The Future of Long-Term Care consultation also took the Active Voice team to Kirkcaldy DRC in November to hear from dozens of local people with personal experience of dementia. We heard about people's current experiences of dementia care and support; learned about what's important to people in terms of their future care and support needs; and listened to their concerns.

The information gained at these consultation events informs our SDWG and NDCAN members who sit on Alzheimer Scotland's Long Term Care Commission, which is exploring new, fairer, more person-centred models of long-term care for older people and people with dementia in Scotland. As part of their work, the Commission's Active Voice members, Kenny Moffat and Tony Worthington (SDWG), and Maureen Huggins and Bill Alexander (NDCAN), visited Croftspar Place in Glasgow. This supported accommodation comprises eight single storey flats for people with dementia, with a housing support and care at home service provided by Alzheimer Scotland. It is a model of care that has been designed specifically for people living with dementia and our visit provided valuable insight into the benefits of such tailored provision.

In November, the team was in Aberdeen for a dementia-focused consultation as part of the co-design process for the Scottish Government's proposed National Care Service, intended to reform and improve how social care is planned and delivered across Scotland. Once again, this event provided an opportunity for us to hear first-hand from people living with dementia, their families, and carers.

Setting out our stall

A busy year of public engagement saw our Active Voice information stand pop up at a host of events and locations across the country. SDWG and NDCAN members took every opportunity to chat with people living with dementia, finding out about what matters most to them, hearing personal experiences and highlighting our campaigning and awareness raising work. This type of engagement helps ensure that the work we do reflects the priorities of people with personal experience of dementia throughout Scotland.



Active Voice hosted **16 opportunities** for Public Engagement



We heard from **over 300 people** with personal experience of dementia



SDWG & NDCAN members had **211 opportunities** to have their say



Our work covered **20 Scottish local authority areas** – more than half the country



Having our say – National & international engagement

Making sure that the collective voices of people with personal experience of dementia across Scotland are heard as widely as possible is extremely important to the success of what we do. We have a long tradition of sharing far and wide our positive campaigning and awareness raising messages, using our experience to help improve how other countries treat people living with dementia, families, and carers.

In 2023, SDWG and NDCAN members were delighted to participate in a number of national and international conferences, helping to ensure that lived experience was at the heart of these events. Additionally, SDWG member Stuart Dougall was one of the faces of Alzheimer Scotland's national Dementia Awareness Week campaign, sharing his experience of young onset dementia and promoting the message that dementia is just one thing about a person, not everything.



Let's Talk About Dementia

In March, SDWG and NDCAN members Margaret McCallion and Marion Ritchie addressed an audience of around 100 health and social care professionals, and those working with older people with dementia and their families, at the 'Let's Talk About Dementia' conference in Glasgow. The conference was designed to provide fresh knowledge updates, a better understanding of dementia, and practical strategies to support the care of people with dementia.

Offering a personal perspective of 'What I Wish You Knew About Dementia and Me', Margaret spoke about her dementia journey from pre-diagnosis onwards. She advocated for the importance of person-centred support, reminding the audience that she is more than 'just someone living with dementia' and encouraging them to 'always see the person, as a person'.

Marion's speech focused on grief from a carer's perspective and highlighted that what is often diagnosed as depression can be symptoms of both guilt and grief. She spoke eloquently about her experience and journey as a carer and called for better support and understanding for those living with a dementia diagnosis and their family.

“Fabulous talk by Margaret McCallion of the @S_D_W_G outlining the power of listening to people with lived experience and reminding us that we are more than our health & diagnoses.” X user

Global Ageing Conference

Later in the year, the SDWG’s Margaret McCallion took her message to the Global Ageing Network’s biennial conference in Glasgow. The conference showcased innovative and forward-looking programmes and approaches from around the world and offered a stimulating forum for the exchange of both practical knowledge and new strategies focused on the provision of high-quality care and support.

In addition to sharing her personal experiences, Margaret also spoke about her aspirations for social care and services as she gets older. She shared how she lives her best life and asked the audience to “see the person, not their age, not their illness but the whole person”. Her message was incredibly well received, with delegates being reminded of the importance of listening to those with personal experience of dementia.



Alzheimer Scotland Annual Conference

This event always provides a great opportunity to engage with a wide-ranging audience of people with experience of, or interest in, dementia, from across Scotland and beyond. Once again, our Active Voice members were at the heart of the 2023 conference which was held in Edinburgh in September. SDWG and NDCAN members Stuart Dougall and Anne Tierney welcomed 400 delegates to the event, while members from both groups introduced the day's three conference sessions, covering innovative work and progressive practice, women's brain health, and research, learning and development.

Opening the first session, SDWG and NDCAN members Christine and Bill Alexander shared their story of living together with dementia. They highlighted the dedication of Alzheimer Scotland's support and services where they live; and spoke about the opportunity they have to shape policy, practice and care through their Active Voice work.

On the topic of women's brain health, NDCAN member Thea Laurie emphasised this must be a priority, highlighting that the concept is not mentioned in the Scottish Government's Women's Health Plan. She called for data on women living with dementia to be included in the Plan, saying, 'it's as if a vital chapter has been missed out'.

"The voices of people with dementia & carers must be at the heart of dementia care, support, policy & practice. Great to hear Stuart Dougall & Anne Tierney share their lived experience & perspectives to bring about positive change #alzscot23" X user

Kicking off the final session of the day, SDWG member Rynagh Flynn shared the personal experiences of her diagnosis; spoke about her membership of Join Dementia Research, her contact with Scottish Brain Sciences, and her participation in dementia research which has offered her hope and helped improve her quality of life.

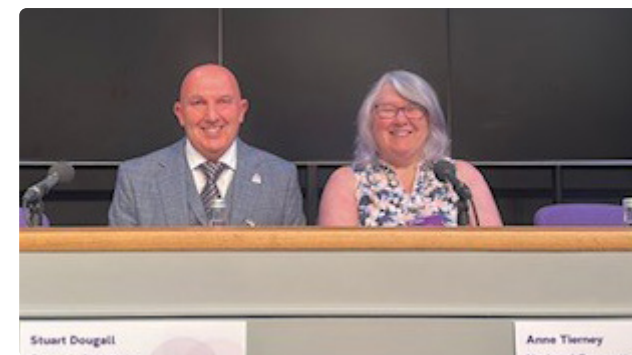
Conference delegates were entertained during lunch by the 'Every Voice Community Choir', including SDWG members Tony Worthington, Danny McDonald and Tommy McLean, and our Active Voice information stand was staffed throughout the day by some of the more than twenty SDWG and NDCAN members in attendance.



Conference webinar series: Who is Alzheimer Scotland's Active Voice?

Following Alzheimer Scotland's successful Annual Conference, the organisation hosted a series of webinars on a range of themes. Our members took this opportunity to promote their work to a wider audience, with SDWG's Kenny Moffat and Patricia Clark, and NDCAN member Joanna Boddy sharing their personal experiences of dementia and the work they do to campaign and influence policy and practice. The webinar is available to view at

<https://vimeo.com/869177194/52f6d82921>



Active Voice in Helsinki

In October, SDWG and NDCAN members flew the flag for Alzheimer Scotland at the 33rd annual Alzheimer Europe conference in Helsinki, joining a delegate list of over 1000 people from 48 countries. Under the banner, 'New Opportunities in Dementia Care, Policy and Research', the members made sure the voices of people with personal experience were heard loud and clear.

The conference enabled our members to discuss their contributions to the Scottish Government's fourth National Dementia Strategy. NDCAN's Elaine Deehan, Barry Northedge, and Anne Tierney presented a powerful recount of the Active Voice engagement with 127 people with dementia and 171 carers to inform the content of Alzheimer Scotland's response to the Government's consultation. The voices of people living with dementia were front and centre throughout, with SDWG's Margaret McCallion treating delegates to an excerpt from her contribution to the academic textbook, 'Occupational Therapy and Dementia', highlighting the importance of creative activities to help people with dementia live well.

Delegates also heard from SDWG member Stuart Dougall about his contribution to an animation working group, researching the role animation can play as a digital solution for sharing rehabilitation advice. Stuart spoke about the animations that have been tested

so far, and shared his own story which has been made into a short animation. These presentations formed the centrepiece of the team's collective effort to bring the perspective of lived experience to bear on an international stage.

The conference also allowed SDWG and NDCAN to showcase a poster presentation depicting our 'Active Voice Toolkit' – created in response to feedback from Alzheimer Scotland frontline staff who hear from people every day about what's important to them, what's working well, and what's problematic in their lives. This generated a lot of interest from delegates keen to hear more about the Toolkit's resources. Beyond the conference sessions, members embraced networking opportunities, renewing past acquaintances while making new connections, sharing ideas, and discussing future projects.

"our Active Voice network members made an outstanding contribution to the success of the conference and were truly exceptional ambassadors for Alzheimer Scotland and Scotland."

*Jim Pearson, Deputy Chief Executive,
Alzheimer Scotland*



Partners in Research & Brain Health

A shared SDWG & NDCAN priority is a commitment to working as partners in dementia research, promoting confident conversations to engage people in research, and supporting the commissioning of purposeful research. Our members are also passionate about promoting information and advice to help maintain good brain health. We were pleased to be able to build on our research partnerships throughout 2023, and to help encourage others to get involved in dementia research.

“With the right support I have no doubt I could have continued to do my job and could still be doing it today.”

Alzheimer Scotland Centre for Policy & Practice (ASCPP)

We were delighted to be able to join our ASCPP friends and fellow partner organisations in March to celebrate the 10th Anniversary of this outstanding facility, which has been at the forefront of driving forward research-informed dementia education, driving up standards in hospital dementia care, and championing innovative dementia research and practice. SDWG and NDCAN have worked as partners with the Centre from the very beginning, contributing to research and supporting students both as advisors and co-researchers. It was an honour for each group to receive 'Inspiring People' awards in recognition of our collaboration with the Centre and contribution to all that has been achieved over the decade. We look forward to the next 10 years as our partnership goes from strength to strength!

An example of our ongoing partnership work with the ASCPP is the 'Career Guidance and Dementia' project, which seeks to develop and test an intervention to support people who are diagnosed with dementia with employment and employment-related decisions. In October, SDWG members Kenny Moffat, Rynagh Flynn and Stuart Dougall recorded an awareness raising film as part of this work, which focused

on working after a dementia diagnosis and offered advice to employers on ways to support someone living with dementia to remain in their job. They spoke about their personal experiences of being in employment when first diagnosed, and gave guidance to those experiencing symptoms of dementia in the workplace.

“I enjoy my work, it's part of me, and thankfully my employer has been supportive in enabling me to continue after being given a diagnosis.”

Looking to the future, SDWG members enjoyed a research-themed 'Tea & Blether' during Dementia Awareness Week 2023 with the ASCPP's Professor Debbie Tolson and Dr Louise Ritchie. Members discussed how we can continue to support research and explored areas for future collaboration which we look forward to taking forward in 2024 and beyond.



“ People with lived experience are at the heart of all we do in the Alzheimer Scotland Centre for Policy and Practice. We are proud that SDWG and NDCAN accepted our Inspiring People Awards which reflect the amazing contributions of individuals, couples and groups to our research projects and education. We listen to and learn from each other and make a difference through our collaborative scholarship.”

Professor Debbie Tolson



Together, we're the change – are you in?

Encouraging others to participate in dementia research is extremely important to our active voice groups. Two SDWG members, Kenny Moffat and Rynagh Flynn, were delighted to be able to be the faces of Alzheimer Scotland's 2023 Winter Campaign which focused on research. The campaign saw Kenny and Rynagh share their experiences of being involved in dementia research and speak about their hope that research is already making a difference for people living with dementia, and has great potential for the future.

The campaign film also featured Professor Tara Spires-Jones speaking about her work and why it's so important for people to get involved in dementia research.

Scottish Dementia Research Consortium (SDRC)

Our support for research sees SDWG and NDCAN members work closely with the SDRC, a community of researchers, healthcare professionals, people living with dementia and others with an interest in research.

We were pleased to attend and participate in the Consortium's 2023 conference in April, where NDCAN members Elaine Deehan and Winnie Henry delivered presentations.

Elaine spoke about the group's research collaboration with the Alzheimer Scotland Centre for Policy & Practice around 'Researching as a family carer', whilst Winnie presented on her involvement in 'Partners in Research'.

Members enjoyed hearing from world-leading researchers as well as early career researchers from all disciplines, and our contribution to research was recognised by a number of presenters at the conference.

The conference also saw the announcement of the first recipient of the Alzheimer Scotland Student Research Programme Award. This was decided by a lived-experience panel including SDWG members Tony Worthington and Kenny Moffat, and NDCAN members Joanna Boddy and Elaine Deehan – a fantastic example of those with personal experience influencing dementia research funding decisions.

Centre for Discovery Brain Sciences

During Dementia Awareness Week, SDWG and NDCAN members met with Professor Tara Spires-Jones, who provided some fascinating insights from the Alzheimer Scotland Brain Tissue Bank. Tara, neuroscientist and Deputy Director of the Centre for Discovery Brain Sciences at the University of Edinburgh is also an Alzheimer Scotland Ambassador. She offered an overview of Alzheimer's disease pathology and discussed how brain tissue donations are advancing knowledge.

Group members heard about how brain tissue samples have taught us important lessons about brain ageing and had the opportunity to look at brain tissue samples showing the build-up of tau protein, which can lead to dementia.

Later in the year we accepted an invitation from Tara to visit the Dementia Research Institute (DRI) at University of Edinburgh. SDWG and NDCAN members were given a guided tour of the 'Spires-Jones Lab' and received fantastic insight into the innovative work the DRI is conducting in the field of dementia research. During the tour, members were shown brain tissue samples used in the research, and were given insightful demonstrations of the lab equipment used

to explore how amyloid and tau proteins affect brain cells. The visit concluded with a discussion with the research professors and other key staff, during which we were able to further explore the work of the Institute and discuss our interest in brain health and research.



Confident Conversations About Research

'Confident Conversations' is an initiative designed to help people who support those affected by dementia to have informed conversations about taking part in research.

In June, SDWG members participated in the Confident Conversations training, provided by NHS Research Scotland's Neuroprogressive and Dementia Network. The training considers what research is, explores the benefits and barriers of taking part, and introduces the 'Confident Conversations Toolkit' which provides information on the routes into dementia research, such as through Join Dementia Research.

Our members thoroughly enjoyed the training which has given them renewed confidence to start conversations about participating in dementia research. They look forward to making good use of these skills in their future work.

Partnership working - Helping people live well & safely with dementia

SDWG and NDCAN members are always keen to support initiatives that help people to live well and safely with dementia. Whether it is policy, practice, research, or technology focused, we want to ensure that our lived experience can help change things for the better and are pleased to be able to work with a wide range of partners to achieve this.



Dementia Guidelines for Person-Centred Care

Our members want people living with dementia to receive the best possible care and support and for over two years NDCAN's Marion Ritchie has worked with Healthcare Improvement Scotland and the Scottish Intercollegiate Guidelines Network (SIGN) to produce a set of guidelines covering assessment, diagnosis, care, and support for people with dementia and their carers.

The new SIGN Dementia Guidelines were published in November 2023 and are the first guidelines for dementia in nearly 20 years. The guidelines provide recommendations based on current evidence for best practice, including a call for more linked up working between different services, better signposting to resources, and efforts to break down the stigma of dementia. The guidelines also recommend more emphasis on person-centred care and a greater awareness of carers' needs. There is also a focus on pre-death grief which can be experienced by people living with dementia, their families and carers, with Marion offering insight into her own experience during her husband Dave's dementia journey.

The SIGN Guidelines booklet is available at <https://bit.ly/47xxsn9>

Welcoming the publication of the guidelines Marion said:

"I think the new guideline will be welcomed by anyone who has been touched by dementia. It offers hope that significant improvements in care can be made and better understanding in general of the disease can be achieved. I'm pleased to see pre-death grief recommendations in the guideline. It is a very difficult issue to deal with and I'm delighted that it is now being properly recognised and highlighted and hopefully, as a result, it can be talked about and supported more widely."



“Being able to get information on dementia from your local library, and take part in dementia-friendly activities, will make a big difference to a lot of people. Spending time with other people in the same boat and being able to make new friends is invaluable. I hope this new partnership means many more people get the help that they need.” Bill Alexander

Libraries partnership

Making sure people have easy access to dementia information and support wherever they live is very important to us so we were delighted to support the launch of a new Alzheimer Scotland partnership to establish dedicated Dementia Information Hubs in over 120 community libraries across Scotland.

The partnership with the Scottish Library & Information Council seeks to build on the many years of working with local libraries and will help Alzheimer Scotland reach more people living with dementia across Scotland. At the launch of the partnership in Stirling Central Library, SDWG and NDCAN members Christine and Bill Alexander spoke about their own personal experiences and of the importance to them of being able to access dementia information, services, and activities locally.



Police Scotland

We are pleased to have established a great working relationship with Police Scotland, with members enjoying several opportunities to engage with police representatives throughout 2023. In February, SDWG members met with the Police Scotland Community Liaison Officer for Argyll & Bute to discuss a range of initiatives including Purple Alert, the Herbert Protocol, and SafeConnect. These initiatives are part of a suite of measures that can support people living with dementia, and our members were keen to learn more about them to promote their increased use.

Our Active Voice Dementia Awareness Week 2023 got off to a flying start when SDWG and NDCAN members hosted an excellent 'Coffee with a Cop' event in Alzheimer Scotland's Glasgow Centre. The event was a great opportunity for people living with dementia to chat with community officers from Police Scotland about the range of initiatives that are available to help people live well and safely with dementia.



Those in attendance shared their personal experiences and gained valuable information. SDWG members also used this opportunity to express their feelings that the term 'Tag' in relation to the 'Dementia Safeguarding Tag' initiative was inappropriate and was an example of the negative language they are trying to eliminate when people talk about dementia. Police Scotland took the feedback on board and subsequently involved SDWG members in renaming this safeguarding scheme, now known as SafeConnect. Later in the year, our Active Voice Communications Group met with an officer from Police Scotland's Cybercrime Harm Prevention team to chat about online safety and cyber security. Staying safe online is hugely important for everyone but can present particular challenges for people living with dementia. Our members will be engaging in further work on this important subject to help keep the dementia community safe.



Scottish Chamber Orchestra

SDWG was pleased to be able to work with the Scottish Chamber Orchestra (SCO) on the organisation of a series of dementia friendly concerts. The first event, a Re:Connect Tea Dance, took place in Edinburgh in February and SDWG members joined a working group to ensure the perspective of those with lived experience was at the heart of all aspects of the arrangements. SDWG's Kenny Moffat contributed to a promotional blog for the concert, speaking about how music has been an important part of his life and his involvement in helping to organise the event. The promotional flyer for the concert also carried a quote from Kenny highlighting the uniqueness of the event due to its informal and friendly atmosphere. We continued to work with the SCO throughout the year as they took their dementia friendly concerts across Scotland.

Dementia Friendly Scotland

SDWG and NDCAN members want to help ensure that communities across Scotland are dementia friendly, with local people, service providers and community leaders working together to make their area welcoming for people living with dementia. An example of this was when SDWG member Tony Worthington visited both Clydebank Library and the NHS Golden Jubilee Hospital in West Dunbartonshire to assist in their efforts to make the venues as dementia friendly as possible. Tony toured the facilities, including the hospital clinical waiting areas and consultation rooms, and was able to provide suggestions for improvements to make them more accessible to those living with dementia.



“As an SDWG member I enjoy doing my bit to improve dementia policy and practice across Scotland, but it’s also important to do what we can in our local communities to deliver positive changes for people living with dementia. That’s why I’ve been keen to lead on initiatives to help make local facilities where I live, such as Clydebank Library and the Golden Jubilee Hospital, more dementia friendly.” Tony Worthington

Sharing our experience - Supporting workforce development

We are committed to doing all that we can to ensure that service provision and workforce knowledge and practice are meaningfully informed by people with personal experience of dementia. Throughout 2023 we were delighted to continue our long-established relationships with colleagues working in health and social care and enjoyed some exciting new opportunities to help inform the workforce of the future.

In conversation with Speech & Language Therapy students

Allied Health Professionals (AHPs) such as occupational therapists, physiotherapists, and dieticians can play an incredibly important role in helping to improve the quality of life for people living with dementia. The SDWG and NDCAN have long enjoyed a close working relationship with AHP colleagues, and members were delighted to have the opportunity to meet with a cohort of first year Speech & Language Therapy Students early in 2023.

The event allowed members to chat with the students about the reality of living with dementia, sharing their personal experiences and providing insights that the students can carry with them as they progress in their career. We received fantastic feedback from the students and are sure that they will be a valuable addition to our AHP community.

"I felt that it was important for me to learn how much variation there is, I had it in my head that everyone had the same symptoms but in fact it is different for all."

"Thank you so much for the opportunity. It was really important for me that a face was put to the condition we are studying & that brain health has opened up to us, a holistic approach."

Getting To Know Me

An important tool to help deliver person-centred care in hospital for a person living with dementia is the 'Getting To Know Me' document, which aims to give hospital staff a better understanding of patients with dementia who are admitted either for planned treatment or in an emergency. The document, developed by Alzheimer Scotland's Dementia Nurse Consultants (ASDNC) and the Scottish Government was first introduced in 2013, so the ASDNCs took the opportunity of its tenth anniversary to review whether it remains fit for purpose. SDWG and NDCAN members were pleased to participate in the review and felt that whilst the document remains important and helped on initial admission to hospital, it did not always impact upon the care received following transfer to another ward. Whilst there was a feeling that the document was person-centred, members' feedback contributed to updating the document to make it more user-friendly and suitable to the needs of those it was designed for.

The image shows a yellow form titled "Getting to know me". At the top, it says "This information will help staff to support you. It will help us get to know you, understand who you are and what is important to you, and how you like things to be. We create you, your family, friends, and care to complete the information and we will do it for you when you are ready. There are guides on the back of the booklet. Please ask a member of staff if you need any help to complete this information." Below this are several sections with rounded corners and light yellow backgrounds, each with a heading and a line for text: "My name: My full name and the name I prefer to be called", "The person who knows me best", "Home, family and things that are important to me: How many people live in your home?", "I would like you to know: anything that will help the staff get to know you, perhaps things that help you sleep or spend your", and "My life so far: This may include your previous or present employment, interests, hobbies, important dates and other information."

Junior doctors

As part of a new initiative, SDWG members were invited to meet with year one and two junior doctors from North Lanarkshire. The medics were keen to meet and chat with people living with dementia outwith a healthcare setting, to hear about their dementia experiences, and to find out more about our active voice work and the support and services provided by Alzheimer Scotland. Of particular interest to the junior doctors were the ways in which members had received their diagnosis, both the good and the bad, and to learn how they were treated in hospital settings as a person living with dementia. Once again, SDWG members were able to provide real life examples to help inform healthcare professionals as they embark on their new careers.



Promoting an Allied Health Professional Human-Rights Based Approach

Our campaigning groups strive to ensure that dementia policy and practice in Scotland respects the rights of people living with dementia and their carers and were delighted to accept an invitation to present at an AHP learning event promoting a human-rights based approach to rehabilitation for people living with dementia.

Held at Napier University in Edinburgh, the event sought to empower a partnership approach to practice and brought together various AHPs from all over Scotland from a range of areas including NHS, social care, and private practice.

NDCAN members Thea Laurie and Barry Gale, and Margaret McCallion from SDWG, all gave personal and impactful presentations. Thea and Barry highlighted that policy suggests that carers should be recognised as equal partners in care, however in practice this is not always the case. Margaret spoke about how basic human rights, which most of us take for granted, are often neglected for those living with dementia.

Edinburgh University & NHS Lothian – Dementia Workforce Excellence in Acute Care

The importance of working in partnership with family carers was the key message from our NDCAN members Maureen Huggins and Barry Gale at an NHS Lothian staff dementia training event. Both members shared their stories of the hospital care experienced by their loved ones with dementia with an audience of around thirty health care assistants. They also gave their perspectives on how they would like staff in hospitals to support people living with dementia and their carers.

SDWG and NDCAN members Margaret and Barry Northedge also delivered an insightful 'in conversation' session during which they discussed the ways in which Margaret is living well with dementia, from her SDWG activities, to taking up running, open water swimming and hill walking!



Engaging with decision makers – Influencing policy & practice

Working with decision makers, such as national government, Ministers, and members of parliament to influence and improve dementia policy and practice has always been a priority for the SDWG and NDCAN. Throughout 2023, our members worked hard to engage as widely as possible with decision makers on a range of matters important to people living with dementia.

Connecting with Members of the Scottish Parliament

We were delighted that almost forty Members of the Scottish Parliament supported a motion submitted by Carol Mochan MSP which noted Dementia Awareness Week at the end of May; recognised that dementia affects young and old alike; commended the work of Alzheimer Scotland and encouraged people to tackle the stigma and raise awareness of dementia. Our members followed this up – thanking those MSPs for their support for the motion and interest in dementia related matters, and to offer to meet with them to discuss some of our key priorities. We were grateful that several MSPs accepted our invitation which provided a valuable opportunity to discuss, in greater depth, what matters to people who are living with dementia. We welcomed the opportunity to chat with MSPs Ruth Maguire, Katy Clark, Stuart McMillan, and Sharon Dowey, during which we highlighted a number of our campaigning priorities and areas of focus.

Sharon Dowey MSP was keen to follow-up on some of these matters and subsequently submitted a series of written questions to the Scottish Government. These included issues such as dementia as a women's health priority; assessing the progress of the first three national dementia strategies; dementia data; dementia diagnosis rates and barriers to diagnosis; and post diagnostic support.

These questions were helpful in trying to elicit an update from the relevant Ministers on the Scottish Government's current position on these important matters. Members from both groups also took the opportunity to speak about them directly with Maree Todd MSP, Minister for Social Care, Mental Wellbeing and Sport, when they met her in October 2023, raising concerns about the gap between dementia policy and implementation; calling for better dementia data in order to help improve supports and services; and making the case for a greater focus on dementia and brain health in the Scottish Government's Women's Health Plan.



We will continue to campaign for action on these areas which are priorities for both the SDWG and NDCAN.

A Commissioner for Older People in Scotland

Our Active Voice members welcomed the opportunity to meet with Colin Smyth MSP to find out more about his proposal to establish an independent Commissioner to promote and safeguard the rights and interests of older people in Scotland. Colin outlined the background to his proposal and explained how an independent voice speaking up for older people could help deliver change in Scotland. He outlined that his proposal would include a legal duty on the Commissioner to consult regularly with organisations who work with and support older people, such as Alzheimer Scotland. This will ensure that the issues taken forward are those that matter most to older people.

SDWG and NDCAN members explored a range of issues in relation to the proposal including specific aspects of the role and functions of the Commissioner, and subsequently submitted a response to the consultation on the proposal. We look forward to continuing to engage on this as it proceeds through the parliamentary process.



Scotland's National Care Service

In 2022, Active Voice members had their say on the Scottish Government's proposal for a National Care Service for Scotland and since then, have been closely following its progress. We want to ensure that the valuable input of people with lived experience helps to shape the development of a service that will deliver meaningful change. Therefore, we were pleased to participate in a National Care Service session called, 'Making Sure My Voice is Heard' in the Highlands in August. Attended by SDWG and NDCAN members Margaret and Barry Northedge, the session explored the issues of accessing social care support. It had a particular focus on issues faced by people in rural and remote locations. Margaret and Barry shared their experiences of living in a rural Highland village, and they, along with the Active Voice team members in attendance, highlighted what's important to people living with dementia, their families and carers in relation to accessing social care support. The session explored aspects of the current system that work well, as well as those that do not, and discussed issues such as the importance of community link workers, and the possibility of ensuring people have a single point of contact to make accessing social care support easier.

As this report is prepared, the Scottish Government is still working towards the introduction of the new National Care Service, and we will continue to ensure the voices of those with personal experience are fed into the co-design process.



Carers Parliament

In November, the Carers Parliament, an annual forum for unpaid carers, carer support organisations and decision makers brought together 150 people in Edinburgh and online. NDCAN members Thea Laurie and Marion Ritchie were there to represent the voice of dementia carers.

The event was an opportunity to hear from, and question, Maree Todd MSP, Minister for Social Care, Mental Wellbeing and Sport, and Councillor Paul Kelly, COSLA Health and Social Care Spokesperson. There were also opportunities to explore a wide range of carer related issues. Thea and Marion participated in a discussion called 'Valuing Care – A Scotland that Cares'. This is also a campaign, supported by Alzheimer Scotland, calling on the Scottish Government to create a dedicated National Outcome on Care and ensure it drives the new actions needed to fully value and invest in care across Scotland.

Throughout the day Thea and Marion hosted an NDCAN information stand – a hive of activity! Conversations were always two-way with lots of new knowledge and information being exchanged, and valuable contacts made. A great opportunity to advocate on behalf of dementia carers.

They spoke about the importance of measuring poverty to improve financial support for carers and spoke about the important role played by women. It was also highlighted that 70% of carers are women, and there's often an impact that caring responsibilities can have on employment prospects and pension contributions for women.



National Dementia Strategy

During Dementia Awareness Week 2023, the Scottish Government published its 4th National Dementia Strategy. Prior to its launch, SDWG and NDCAN members worked tirelessly throughout

the consultation process. They facilitated a series of public engagement sessions, gathering input and opinion, so that the voices of lived experience could inform this important policy document. The ways in which the new 10-year Strategy are to be delivered will be laid out in rolling 2-year delivery plans – the first of which was due for publication in early 2024. Members from both groups were invited to join the Care Partners and Resilient Communities sub-groups set up by the Scottish Government to help develop the delivery plans. Through our membership of these groups, we will continue to ensure that the personal experiences of people living with dementia are made known to those responsible for improving and delivering dementia policy and practice in Scotland.





**For more information on
both Active Voice groups:**

Email:

activevoice@alzscot.org

Website:

www.alzscot.org/sdwg

www.alzscot.org/ndcan

Twitter:

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

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

Telephone:

0141 410 1171



ndcan
National Dementia Carers
Action Network