



Alzheimer Scotland
Action on Dementia

Alzheimer Scotland
Action on Dementia
Prevent. Care. Cure.
The 31st General Meeting of Alzheimer Scotland - Action on Dementia November 2024

(POS3-18) 'For Carers, By Carers' National Dementia Carers Action Network (NDCAN)

About us
The National Dementia Carers Action Network (NDCAN) is a member-led national group for carers, and former carers, of people with dementia in Scotland. The campaigning and awareness raising group exists to make the voices of dementia carers heard, raising awareness of the issues impacting on Scotland's carers and to ensure the voices of carers are heard and represented.

'For Carers, By Carers'
In 2023, NDCAN members took part in a conference on building resilience in carers. The conference was held in Glasgow and was a success in helping other carers to feel supported and to share their experiences of what has helped them.

For Carers, By Carers
The group agreed for funding and the Life Foundation to support them to develop a series of eight booklets, exploring what has helped carers of people with dementia to get through the day and cope with difficult times. These booklets offered words of encouragement, tips and advice.

An update for 2024
In 2024, NDCAN members shared the resources to ensure they remain current and effective. Revisiting digital developments, they highlighted that technology and apps are vital tools for carers, and they reflected on updates to dementia care and practice. Each booklet now stands on its own, sharing information specific to relevant areas of dementia care, as well as providing top tips and general advice.

The 8 booklets are:
- Helping carers to live with dementia
- Living with dementia
- Moving into care home
- Looking after yourself
- Dementia in care
- Dementia in care
- Dementia in care
- Dementia in care

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

Active Voice Annual Report 2024

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

the scottish
dementia
working group

ndcan
National Dementia Carers
Action Network

Welcome

Wendy Rankin-Smith, Active Voice Lead, Alzheimer Scotland

2024 was an important year. Never before has our Annual Report reflected on such a promising time – with pioneering research in the field of Alzheimer’s drug developments attracting global attention, renewed focus on the importance of brain health, and a range of high-profile events designed to highlight the impact of dementia on communities around the world.



Active Voice has continued to work alongside Alzheimer Scotland to maintain the momentum, ensuring that the voice of lived experience is heard loud and clear. We want to inspire the dementia community to have a say in decisions that affect their daily lives, and campaign for a system that sees funding and support services aligned with those they are designed to serve.

Things haven’t always gone the way we’d have hoped, and our members are disappointed by the decision to abandon plans for a new National Care Service. For a long time, we

have highlighted the need for change and improvement to Scotland’s social care system for people affected by dementia. We believe that change is still desperately needed.

This report looks back on some of the year’s activity and gives an insight into the work of our two national Active Voice groups – the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN). We would like to thank everyone who has supported our work over the last twelve months, from those who shared their personal experiences of dementia with us, to our many partners who work hard every day in the fields of dementia research, care, policy, and practice. We couldn’t do what we do without your support.

2024 was also tinged with sadness, as we lost three wonderful Active Voice colleagues, Christine, Archie, and Ian. In tribute to them, we will embrace 2025 with determination, optimism, and hope – their legacies living on through our work to positively influence the worlds of dementia prevention, care, and cure.

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Foreword

Henry Simmons, Chief Executive, Alzheimer Scotland

It is an honour for me to be writing this introduction for this year's Active Voice Annual Report. The hard work of our two Active Voice groups – the Scottish Dementia Working Group and the National Dementia Carers Action Network has continued over the last twelve months and the dedication of the members is truly remarkable.



As always, the voice of people with lived experience is at the very heart of Alzheimer Scotland's work and I hold in high regard the opportunity to meet up with Active Voice members on a regular basis and hear directly from them about the issues that are affecting the dementia community.

Over the last year, Active Voice group members have given their time and energy to campaigning, awareness raising and challenging stigma. They have taken part in conferences and events both at home and abroad, met with a range of students to talk about their experiences of living with dementia or caring, and visited our Centres to hear what people are saying in local communities.

A key focus for Active Voice is research, and their visits to the Centre for Discovery of Brain Sciences at the University of Edinburgh mean that members are kept up to date with what's happening in dementia research. Like Alzheimer Scotland, Active Voice members believe that 'research is hope' and by participating in research themselves, they are helping to drive forward this vital work. 2024 saw a lot of developments in the world of research including the promising results from trials of Alzheimer's disease drug treatments. I know that Active Voice members are hopeful about what this could mean for future generations.

I'd like to finish by thanking each and every Active Voice member for their contributions over the last year. You will see in this report just how much they have achieved in a relatively short period of time – it is inspiring. I must also thank the Active Voice staff team for the support they provide.

I look forward to working with Active Voice in 2025 and in the years ahead.

Henry Simmons

Introductions from Active Voice members

SDWG members

– Rynagh and Margaret

Campaigns, conferences and consultations, research and brain health – 2024 was another busy year for SDWG and NDCAN members. With opportunities to provide input into a diverse range of projects, from political, medical, care and support areas, to human rights issues – it's clear that being heard and included plays a significant role in our wellbeing – and is always appreciated.



This year, one of the highlights was the Alzheimer Scotland Annual Conference. It was wonderful to hear from so many inspirational people. Active Voice members took the theme of 'personhood' and ran with it, as we shared a little insight into our lives under the banner, 'See me, not my dementia diagnosis'.

On the international front, the Alzheimer Europe Conference in Geneva focused on 'New Horizons: Innovation for Dementia' and was a wonderful opportunity to share ideas and appreciate the work that is being done in Scotland. Having representation on the European Working Group for People With Dementia (EWGPWD) has given SDWG and Alzheimer Scotland an international voice to communicate experiences, policies and practices from Scotland. Attending and presenting in Geneva was also a highlight – being up on the stage sharing collaborative work as we challenge stigma, promote our key priorities and focus areas. And not forgetting 'poster day', where we were able to showcase the work of Active Voice – this always gives great networking opportunities.

Throughout the year, Alzheimer Scotland and the Active Voice staff team have got us where we need to be and supported us every step of the way.

With much appreciation and thanks.

NDCAN members

– Bill and Frank

Over the past year, NDCAN members have embraced an extensive schedule of activities, all designed to accelerate action in the fields of dementia prevention, care, and cure. We have continued to provide insights based on real life experiences to inform campaigns, conferences, consultations, and research projects – both in Scotland and with peers across the globe.



We have supported the NHS to enhance and develop their staff training and made suggestions for the improvement of services for people with dementia. And, we have pressed on with our engagement with Scottish Government Ministers, academics and researchers. We strongly believe that the voices of carers should flow directly to politicians – who, along with medical and social services, must show commitment to positive change in dementia policy.

We have continued our work with our Allied Health Professional colleagues, sharing ideas with skilled practitioners and university students to identify the key competencies needed to improve frontline services. And, we have contributed to research into the use of artificial intelligence in the care sector, considering how technological advances could help our loved ones live well with dementia.

A highlight of the year was providing input to Alzheimer Scotland's Long Term Care Commission and report which involved the exploration of alternative models of care. We look forward to positive action following the report recommendations.

Finally, we would like to extend a warm welcome to new members who have joined our ranks in the last year. We are thrilled to have you with us as we share the diverse voices of carers across Scotland. Welcome aboard!

What is Active Voice?

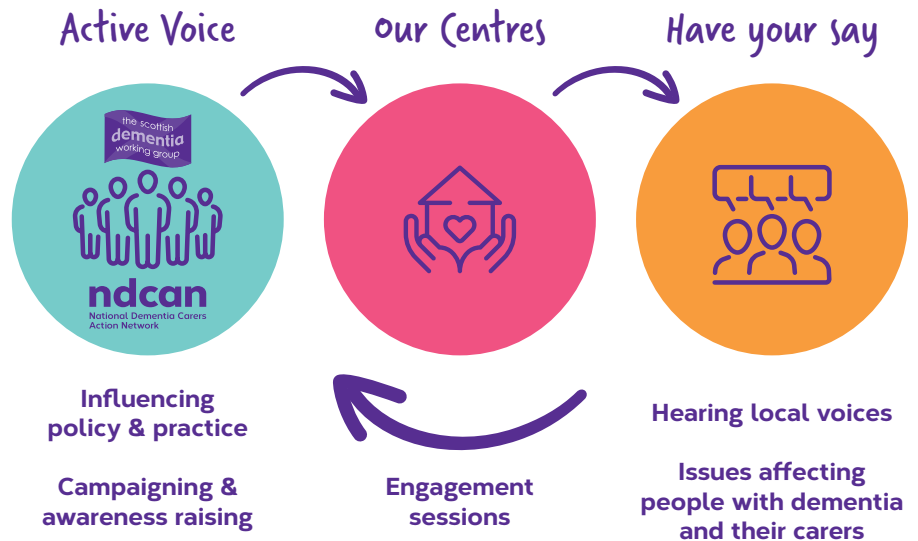
Active Voice is the collective, independent voice of those with lived experience of dementia, sitting at the heart of Alzheimer Scotland. We empower people who are living with dementia, and current or past carers, to have their say – and we carry these voices far and wide through highly successful campaigning and awareness-raising efforts. The Active Voice network comprises three distinct elements:

- The Scottish Dementia Working Group (SDWG)
- National Dementia Carers Action Network (NDCAN)
- Local engagement initiatives

Our main objective is to enable and promote the diverse voices of people who are living with dementia and their carers to campaign for and uphold rights, and drive change.

We campaign for the rights of people impacted by dementia and are committed to ensuring that these principles are upheld so that every person affected by this condition has choice and control, as well as the innate right to self-determination, inclusion, and equality.

Our strong and assertive collective voice speaks for those who feel powerless, and tackles head-on the challenges we face as a dementia community. We continually ask questions about the meaningful change we would like to see in the dementia arena and plan the most effective way to achieve that objective. To that end, we support a wide campaign cycle – not only to raise awareness and advocate for dementia in local communities, but also to influence policy and practice, support research, and change the overall perception of dementia.



Throughout 2024, we have attended national and international conferences to promote our work and learn from others, contributed to policy motions such as the Fair Dementia Care and LongTerm Care Commission, and collaborated with the health and social care sector to train its workforce.

New members are always warmly welcomed, but we also understand that joining a national campaigning group isn't for everyone. That's why a focus for us is to reach out and hear the hidden and quieter voices across Scotland.

Our Active Voice toolkit ensures that everyone who wants to express their views about living with dementia can do so in a way that suits them.

Information is captured in a variety of ways – from face-to-face 'Have your say' sessions in localities across the country, to 'Share your story' postcards and 'Today I'm thinking about...' templates which can be completed anonymously.

This mechanism enables us to capture invaluable information about what people across Scotland think and feel about living with dementia, what helps them, and what they feel needs to change.

About the Scottish Dementia Working Group (SDWG)



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.

Founded in 2001, this 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 so that people living with dementia can influence policy and practice, and acting as partners in dementia research.

The crux of our work is to:

- campaign and raise awareness at a societal level
- engage with, and inform, Scotland's National Dementia Strategies
- work with stakeholders including national and local government, private and voluntary providers of health, social care and housing, and other relevant bodies
- promote dementia among health, social care and other related professions
- collaborate with other representative groups, including our sister group NDCAN
- work in partnership with Alzheimer Scotland staff to ensure coordinated and effective campaigning activities

For more than 20 years, SDWG members have raised our voices and called upon our firsthand experiences to help make things better for future generations across Scotland. More widely, we have engaged with international dementia organisations to influence and shape global dementia policy.

Every year, SDWG agrees a list of priorities that align with our values and long-term goals. By setting out these areas clearly, we can focus our efforts on what truly matters while maintaining Active Voice's overarching themes of human-rights and equality.

Priorities & Focus Areas 2023-2024

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 and services, such as post diagnostic support (PDS)



Brain health

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



Influencing policy & practice

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



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



**Human rights of people
with dementia**



About the National Dementia Carers Action Network (NDCAN)



NDCAN is a national, member-led campaigning and awareness raising group, established for current and former dementia carers in Scotland.

With a wide general membership, the group provides a platform for those who care for people with dementia, empowering them to influence and inform policy and practice in the dementia arena. Members have a diverse set of circumstances, and believe it is important that all backgrounds and cultures are represented. Dementia does not discriminate – and this notion sits at the core of NDCAN, with members strongly advocating that the distinct experiences, thoughts, and opinions of those directly impacted by dementia should be what steers dementia policy and practice.

For fifteen years, we have:

- campaigned for better carer supports and services
- encouraged a person-centred approach for people living with dementia and their carers
- sought to ensure that dementia policy is informed by those it affects
- contributed to the development of research that has significant impact
- resolutely engaged with Government and Parliament, meeting regularly with MSPs, responding to consultations, and participating in national forums to ensure carer voices are heard

In the same way as SDWG, each year NDCAN establishes a set of priorities, informed by individual experiences and those we learn of through national engagement with the dementia community. These focus areas guide our activities and decision-making processes, which are always supported by Alzheimer Scotland's dedicated Active Voice staff team.

Priorities & Focus Areas 2023-2024



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.

Human Rights

Equality & Diversity

Having our say – local engagement

To strengthen our campaigning and awareness-raising efforts, getting out and about into local communities is non-negotiable for our Active Voice groups. Throughout 2024, we have continued to build community connections because we believe that only by doing so can we really understand the complex issues that affect people living with dementia. It is our mission to emphasise the influence of lived experience and empower those who are impacted by dementia to have their say. Over the last year, our members have embraced opportunities to visit communities, chat to people about their everyday experiences and craft our campaigns from the ground up.



Active Voice information stand

Our group members are always keen to spread the word about Active Voice and listen to the quieter voices of those who are impacted by dementia – and we use a variety of ways to reach people!

This year, we've attended a range of dementia-specific information days at organisations across the country. For example, during Dementia Awareness Week in May, we were only too happy to take our information stand along to West Lothian College for an event organised by West Lothian's Post Diagnostic Support team.

Marion from NDCAN and Rynagh from SDWG represented Active Voice, with attendees including local people who currently receive, or are waiting for, post diagnostic support. Marion and Rynagh enjoyed the chance to offer peer support and chat to people about life with dementia. It was also a great opportunity to spread the word about our work and drive home our message that the voice of lived experience really does matter – with Active Voice providing the platform for anyone impacted by dementia to have their say.



Forget-Me-Not

Also in May, we got out into communities across Scotland to support Alzheimer Scotland's nationwide fundraising campaign in partnership with Morrisons supermarkets.

During the Forget-me-Not appeal, Active Voice staff and members, along with Alzheimer Scotland colleagues, joined an army of volunteers within local Morrisons stores to raise awareness and raise vital funds. We wore smiles and our iconic purple sparkly badges to spread the word about Alzheimer Scotland services, chat to people about life with dementia, and encourage donations. It was a wonderful opportunity to get into the heart of communities and let people know about the support available if they need it.

Active Voice Lead, Wendy Rankin-Smith and Active Voice Development Officer, Norie Williamson led the way, getting into their local stores to highlight the work of Alzheimer Scotland and Active Voice.

Out and about

Our members always jump at the chance to get out and talk to people who are affected by dementia – to learn about their lives and spread the word about Active Voice initiatives. It's so important that we listen to the experiences of others, as well as share our own.

Central to that is hearing from those who access Alzheimer Scotland's Brain Health & Dementia Resource Centres (BHDRCs) and those who receive support from Alzheimer Scotland staff in their local areas. By visiting these Centres, working alongside Alzheimer Scotland colleagues, we can capture these stories in many creative ways. For example, we've used photography, case studies, quotes, blogs, and short films to paint a rich picture of the reality of living with dementia in Scotland today.

In August, SDWG members Tony and Tommy called into the Centre in Bearsden. They were delighted to meet with and chat to those who were using the Centre, and benefit from the wide range of support and dementia resources available. And of course, they took the opportunity to share information about upcoming Active Voice initiatives and issue a warm invitation to anyone who might be interested in joining one of our groups.



Young Onset Support Group

In October, SDWG and NDCAN members Stuart and Lorraine Dougall paid a visit to Alzheimer Scotland's Centre in Alloa for the launch of a new young onset support group. Stuart, who is living well with a diagnosis of young onset Alzheimer's disease, is enthusiastic about the benefits such a group will bring to the local community. Taking place in a welcoming, familiar, and dementia-friendly space, groups like these are designed to offer a platform for those who may feel less comfortable sharing their voice, enabling them to contribute their thoughts in a lower-key way.

During their visit, Stuart and Lorraine emphasised the value of these local groups and outlined how important the voice of lived experience is when it comes to raising awareness, stressing that 'every voice matters'. They also provided an insight into Active Voice's broader campaigning efforts and took the opportunity to support local Dementia Advisors Cherie Raby and Donna Patterson by offering group members encouragement and positivity about living well after a diagnosis.



Livingston legend

Stuart is also a very familiar face at his local Centre in Livingston. He is so passionate about spreading the word of Active Voice and supporting others who are living with dementia, he very kindly volunteers his time to offer a regular 'meet and greet' service. Stuart's energy is contagious - he's able to connect with visitors to the Centre in such a positive way that he's become a much valued and respected member of the team. He is also frequently called upon to support our Alzheimer Scotland colleagues in other aspects of their work. For example, he has offered important insight during a recent staff recruitment drive, providing the voice of lived experience as part of the interview panel. Thank you, Stuart!

"Stuart supports us with events, open days, the promotion of our service, and awareness sessions as well as speaking to visitors at our Centre about his lived experience. His personalised contribution to our service is immeasurable - he is an active and much valued member of the West Lothian Team."
- Lauren Heap, Centre Manager



Share your story... Living with dementia

Our Active Voice campaigning and awareness raising is informed by the personal experiences of people living with dementia, their friends, family, and carers. Use this postcard to share an experience you'd like us to know about.

What helps?

Active Voice

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



Alzheimer Scotland
Active Voice



The Scottish dementia writing group



ndcan
National Dementia Carers
Active Network

Tea and Blether with the Dementia Dogs

SDWG and NDCAN members always welcome the chance to get together to discuss important issues and a 'Tea and Blether' event in the Glasgow Centre gave us the perfect opportunity to do just that in a relaxed setting. Following tea, coffee and cupcakes, members met with Dementia Dogs, Josie and Sandy. Then we enjoyed an insightful presentation from the Dementia Dogs project which explained how the trained dogs can provide support to a person living with dementia by prompting daily routines.

Following the presentation, everyone looked out their pens and dabbers for a fun game of Doggy Bingo – and Josie and Sandy were only too pleased to show off their skills by drawing the numbers.



Peer support

In November, SDWG member Rynagh went along to a peer support group at Alzheimer Scotland's Edinburgh Centre. This group has been established for those who are waiting to access the Memory Assessment and Treatment service and offers the chance for people to come together in a relaxed and informal setting and chat about their experiences.

It also provided a great forum for Rynagh to present some of our Active Voice initiatives and encourage people to have their say in a way that feels comfortable for them.



Christmas cheer

As the year came to a close, Active Voice members were delighted to gather for our traditional Christmas get-together. This brought members of both SDWG and NDCAN together to enjoy a friendly atmosphere, with festive food, fun activities, and good company. We also participated in the infamous Active Voice annual quiz, with another resounding win for our reigning champ Kenny Moffat. Well done, Kenny!



Having our Say – national and international engagement

According to the World Health Organization, 55 million people are currently living with dementia worldwide. This startling statistic demands global attention, so it's not surprising that our Active Voice groups are keen to engage with policy makers and those with lived experience both home and away. Throughout 2024, SDWG and NDCAN embraced a packed schedule of conferences and events that took us across Europe and enabled us to share awareness raising messages with peers from around the globe.

Alzheimer's Disease International Conference, Krakow

Alzheimer's Disease International (ADI) kicked off proceedings in April, with their conference in Krakow, Poland. Under the banner, 'Dementia: Insights; Innovations; Inspirations', this gathering brought together global experts to share achievements, innovations and accounts of best practice in dementia research, care and policy – while continuing to address and challenge the perceptions of dementia.

Representing Alzheimer Scotland and Active Voice were staff member Norie Williamson and NDCAN member Joanna Boddy, who joined over 1000 delegates from more than 120 countries. They were honoured to attend such a prestigious event, but even more delighted to deliver a presentation called 'Every Story Matters', complemented by a poster presentation to highlight our 'Coffee with a Cop' initiative. As people directly affected by dementia, their personal accounts were powerful and their presentation concluded with the famous – and much endorsed – quote from Professor Tom Kitwood who said, "When you've met someone with dementia, you've met someone with dementia".

Following the conference, Joanna said that while Alzheimer Scotland leads in the fields of prevention, care and research in Scotland, there is still great opportunity to learn from the experiences of other countries. We look forward to doing just that at the next ADI conference in Lyon, France in 2026.

"I was a daughter first and didn't think of myself as a carer for a long time – like many family carers. This can mean our voices are often not seen or heard, or our needs recognised. As part of NDCAN I campaign to make sure they are and that we are valued and seen as equal partners in care." – Joanna





The Alliance Conference

Next up was the Alliance Health and Social Care Conference held in Glasgow in May. The Alliance is the national third sector intermediary for health and social care organisations and is a strategic partner of the Scottish Government.

"The Alliance vision is for a Scotland where people of all ages who are disabled or living with long term conditions and unpaid carers have a strong voice and enjoy the right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre."

SDWG member, Kenny Moffat, was invited to attend and present at the conference which covered three fundamental areas: 'Our Voice, Our Rights, and Our Future'.

Coinciding with the conference timing, Alzheimer Scotland's Commission on the Future of Long Term Care in Scotland report was also published in May. This set out recommendations to improve the existing landscape and deliver an ethical commissioning strategy for long term care, exploring a range of alternative care models and approaches for consideration.

These themes were explored further at the conference and following an opening keynote speech from Neil Gray, Cabinet Secretary for NHS Recovery, Health and Social Care, Kenny contributed to a panel discussion on 'a new vision for long-term care'. The panel included Former First Minister Henry McLeish, who is Chair of Alzheimer Scotland's Long Term Care Commission, of which Kenny is also a member. Kenny took the opportunity to share his experience of receiving a dementia diagnosis and spoke about Self-Directed Support being his chosen long-term care option.

He was also able to participate in a range of interactive workshops, which offered delegates the chance to share their knowledge and experiences of health and social care services, listen to accounts of challenges caused by stigma, and discuss ways to make sure that dementia research remains person-centred.

"An excellent forum for discussion, ensuring that lived experience is part of any conversation regarding health and social care and the future of long-term care." - Kenny

Alzheimer Scotland Annual Conference

In September, Active Voice was once again at the heart of Alzheimer Scotland's own Annual Conference. SDWG and NDCAN members were not only part of the welcome reception but introduced each of the five conference sessions.

Tommy, Maureen, Rynagh, Fiona, Marion, and Stuart each provided insights into their own lives, reflecting the importance of 'personhood' which was one of the key themes of the day. SDWG's Tommy McLean, along with NDCAN's Marion Ritchie opened the conference, with their personal accounts setting the perfect tone. Tommy lives with frontotemporal dementia, and he took the opportunity to remind everyone that dementia is about so much more than memory loss. He talked about his daily life and shared an inspirational account of how exploring new interests helps him live well with his condition.

Tommy and Marion used their platform to explain how empowering they find being part of a group that is so engaged with advocating for positive change and raising awareness. They also spoke eloquently about the value of personhood, emphasising how important it is to see the person first, rather than defining a person by their diagnosis.



"Dementia impacts my judgment, my eyesight, my mood, as well as my memory. But let me be clear: the person I am remains unchanged. I may have dementia, but dementia does not define who I am." - Tommy



Rynagh gave an insightful presentation about why practice innovations are so important to improve outcomes for those who access social care services, while Fiona gave a poignant account of caring for her husband and why she thinks ambitions for positive change in long-term care must be achieved.

During lunch, Tommy performed as part of the 'Every Voice' Community Choir, alongside fellow SDWG members Tony Worthington and Danny McDonald while the Active Voice information stand enjoyed a passing crowd of over 400 people.

Alzheimer Europe Conference, Geneva

In October, we made our way across Europe again – this time to the beautiful Swiss city of Geneva for the 34th annual Alzheimer Europe Conference. SDWG and NDCAN members, Rynagh, Margaret, Maureen, and Thea attended on behalf of Active Voice, enabling them to connect with new people in this rich learning environment. They were each delighted to deliver a presentation, sharing the work of Active Voice and their individual experiences under the themes of 'Dementia Work Force', 'Public Involvement in Research', and 'Young Onset Dementia'.

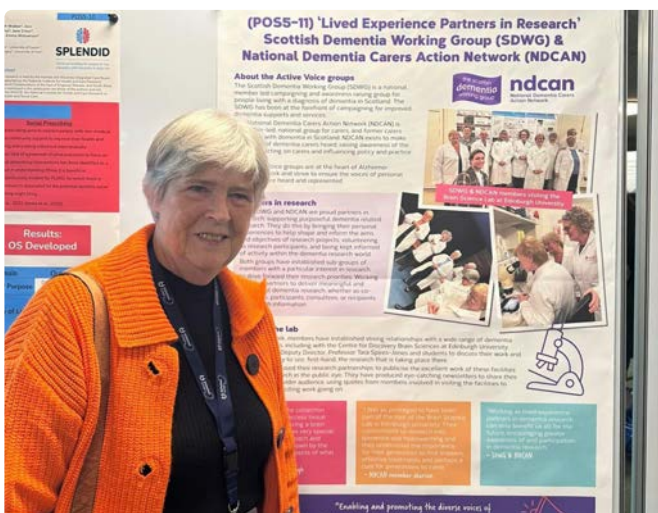
As a member of the European Working Group for People With Dementia (EWGPWD), SDWG representative Margaret took to the stage in a session entitled, 'People living with dementia'. Margaret delivered a powerful account of how she has come to terms with her diagnosis and is now 'living her best life'. She received much praise for her openness, honesty, and optimism from the audience.



It was Rynagh's turn on day two, and she chose to share her experience of being part of Alzheimer Scotland's 2023 winter campaign 'We're All In', which focused on dementia research. Rynagh shared her hopes and wishes for the future of research and emphasised the importance of including people with lived experience. She highlighted that the campaign reached more than 150,000 people and concluded by telling the audience, ***"Research is one way for me to find out about progress, find out more about what's being done, what's out there and to meet other people."***

On day three, NDCAN members Thea and Maureen took a very different approach for their presentation – deciding to try a more unique way of explaining how Active Voice supports workforce development. Rather than standing behind a lectern, they had an open conversation, 'interviewing' each other as they spoke about the work NDCAN does and how they have each contributed to it. Both gave passionate accounts of why they choose to be involved with NDCAN and issued a joint plea to the professionals in the audience to 'please involve the family' when supporting someone with dementia. Finally, they used their platform to signpost delegates to Alzheimer Scotland's newly revamped suite of information leaflets, 'For Carers, by Carers'.

We are looking forward to the 35th annual conference to be held in Bologna, Italy in October 2025.



Meeting of the European Working Group for People With Dementia (EWGPWD)

In December, Margaret McCallion of SDWG, made a festive trip to Brussels for an in-person meeting of the European Working Group for People With Dementia. Established by Alzheimer Europe, the group is composed entirely of people with dementia, who are nominated by their national Alzheimer associations. They work to ensure that the activity of Alzheimer Europe reflects the priorities and views of people living with dementia.

Over a busy two days in the Belgian capital, Margaret had the opportunity to network with peers from across Europe and learn about their experiences of living with dementia. Members were invited to a debate at the European Parliament which focused on 'Dementia research as a European priority'. This celebrated recent advances in dementia research and provided an overview of current initiatives.

Next, the group discussed how advances in artificial intelligence (AI) and robotics may impact the future of care provision and shared their views on inequalities in dementia care. Members also held conversations with academic researchers and doctoral students to ensure their studies are informed by the voices of lived experience. Their input was sought on the impact of dementia on relationships, home living environments, and how people affected by dementia access information, care, and support in their community.



European Dementia Carers Working Group

A sister to the European Working Group for People With Dementia is the European Dementia Carers Working Group (EDCWG). Members include current carers, relatives and supporters of people with dementia, and those with prior experience of caring.

Together, they strive to ensure that the priorities and views of carers are represented in all Alzheimer Europe activities. NDCAN member Barry Northedge is an active member of EDCWG and works with colleagues to ensure that the voice of carers is heard.

"Both groups, sponsored and hosted by Alzheimer Europe, are representatives of Alzheimer associations from across Europe who come together to share experiences, views and knowledge to help shape research into Alzheimer's disease and dementia."

"The groups meet regularly online and in person to discuss pertinent topics and meet researchers who are keen to incorporate lived experience in their work. Members bring their own perspectives to the discussions – we are not here to share a corporate message."

It is fascinating to see the diverse approach to dementia across Europe, we can learn so much from each other's experiences.

"The highlight of each year is the annual Alzheimer Europe Conference, last held in October in Geneva. This brings together oral and poster presentations of research and work from across Europe. It is heartening to note that Scotland is always extremely well represented, and, sharing much of the innovative work that we are part of. Active Voice leads the way! Lived experience is at the heart of the conference and is integral to all presentations and plenary sessions."

"Over the past year both groups have been involved in discussions around palliative care, new treatments and early/pre-symptomatic diagnosis. We are privileged to hear firsthand from the pharmaceutical companies producing treatments such as donanemab and lecanemab and be involved in advisory groups helping to shape future research. This involvement is interesting and informative – though can be challenging when 'wrestling' with any ethical and moral issues that arise. However, it is always worthwhile."

– Barry Northedge, NDCAN

Partners in research and brain health

Thanks to the latest studies, we are learning more than ever before about dementia and what is most important when it comes to care, support and quality of life – but also what can be done to help protect brain health throughout life, and work towards finding a cure for dementia. Active Voice believes it's crucial to maintain this momentum and throughout 2024, have continued to celebrate the idea that each of us, in our own way, can contribute to the multifaceted landscape of dementia research. It's not all about white lab coats and test tubes – research can take many forms.

Scottish Dementia Research Consortium (SDRC) Conference

We welcomed the arrival of summer with a trip to Dundee for the 2024 SDRC Conference. With a theme of 'Celebrating Scottish Research and Collaboration', the event was jointly organised by SDRC, the NHS Neuro-progressive and Dementia Network, and the Brain Health ARC.

Active Voice was delighted to staff an information stand during the two-day event, which proved to be a popular destination for delegates keen to learn more about the campaigning and awareness-raising efforts of SDWG and NDCAN. This helped to boost our profile and enabled networking opportunities between those with lived experience and research academics and professionals.

Day one featured an overview of Alzheimer Scotland's Student Research Programme. Funding studentships at higher education institutions across Scotland is an innovative way to support the next generation of dementia professionals, and one which draws significant interest. Each year, SDWG and NDCAN members lead a competitive process to select a study project, with Kenny, Tony, Joanna, and Elaine being involved since the programme's inception in 2022. Conference delegates enjoyed a pre-recorded video of group members expressing the importance of the programme, followed by a presentation of this year's project – 'Trauma and dementia diagnosis'.

On day two, a session entitled, 'Experts with lived experience', featured presentations by Margaret, Stuart and Rynagh from SDWG and Frank, Marion and Elaine from NDCAN. Their compelling personal stories emphasised how people experience dementia differently, and these experiences are all invaluable for the effectiveness of research, increasing awareness and improving support for those who need it.

Active Voice members Thea Laurie and Tommy Mclean also represent NDCAN and SDWG on the SDRC Committee to provide insight, information, and advice from an Active Voice perspective. This ensures that we remain abreast of current research priorities and gives us the opportunity to collaborate with researchers, policymakers, funding bodies, and members of the public who are interested in learning more about dementia and brain health.



Centre for Discovery Brain Sciences visit

As proud partners in dementia research, SDWG and NDCAN have established a strong relationship with the Centre for Discovery Brain Sciences at Edinburgh University. Having met several times with Centre Director, Professor Tara Spire-Jones and students to discuss their work, many of our members have also had the opportunity to tour the facility and see firsthand some of the research being undertaken there.

In February, six of our SDWG and NDCAN members had the pleasure of visiting the centre again. Professor Spire-Jones and her team gave them an insight into some fascinating live projects, including 'living' tissue brain research and fruit fly brain research. Members were also given the chance to try out specialist equipment, such as state-of-the-art microscopes as well as hear more about the ethics and protocols of the centre.



I feel so privileged to have been part of the tour of the Brain Science Lab in Edinburgh University. Our meeting with Tara, Claire and their students and listening to everyone's enthusiasm while giving summaries of their work was inspiring. Their commitment to dementia research is heartwarming – they understand the importance of their generation to find answers, effective treatments and perhaps a cure for generations to come.

The lab tour itself was fascinating. Hearing about their strict ethical collection and use of small pieces of 'living' brain tissue from brain tumour operations, as well as post-mortem tissue was inspiring. It was just incredible to learn how much they could do with tiny pieces of brain tissue the size of a crumb, and thin slices which could be layered into even thinner slices then combined again.

The different kinds of microscopes being used for different kinds of tests was interesting too. They use state of the art technology so expertly – I was just overwhelmed with their knowledge and skills, and their ability to explain their work in lay terms that we could all understand and appreciate. – Marion, NDCAN

Meeting with Brain Health Scotland

Over recent years, brain health and research have emerged as priority topics, and in 2020 Alzheimer Scotland launched a dedicated 'prevention' initiative called Brain Health Scotland. Established to reduce the incidence of dementia in Scotland over the next ten years, activity focuses on key risk factors that are associated with the development of the condition. With the World Health Organization also launching its first paper on the importance of optimising brain health throughout life, it's no surprise that these issues now feature as significant areas of interest for SDWG and NDCAN.

In December, members were invited to the Centre in Glasgow to meet with Hugh Masters, Brain Health Policy Consultant for Alzheimer Scotland. Hugh provided an update on the progress of the Brain Health Clinic in Aberdeen, the first of its kind to open in the UK and NDCAN's Marion Ritchie, who co-chairs the Brain Health Scotland Professional Advisory Forum, was able to update us on clinical and professional input offered by multidisciplinary stakeholders.

Following this interesting segment, we switched our focus to the concept of risk, and talked about risk reduction strategies, prevention, and modifiable risk factors. Members of SDWG and NDCAN were invited to share our perspectives on these topics, as Hugh shared the findings of the recent Lancet Commission's report which identifies 14 modifiable risk factors that can be addressed during early, mid, and later life.



Active Voice research subgroup

When it comes to research, we always want to be 'in the loop' – and our dedicated research subgroup ensures that we never miss any important updates nor any opportunity to contribute in a lived experience capacity.

During 2024, we have worked to establish a strong link with Alison McKean, Alzheimer Scotland's Executive Lead for Brain Health and Research. This connection means that we're kept updated with developments from Alzheimer Scotland, the Scottish Dementia Research Consortium (SDRC), and Alzheimer Scotland's Centre for Policy and Practice (ASCPP). We participate with regular online meetings and are in the middle of discussions about providing representation to the SDRC and ASCPP steering groups.

Women's brain health

Throughout 2024, Active Voice also campaigned for women to have equal recognition in national brain health policy development. We believe that women have been largely overlooked when it comes to this, and that inequalities can be detected in everything from the prevalence of the disease through to disparities in diagnosis, and access to treatments.

With dementia now the leading cause of death for women in Scotland, as well the fact that women make up the biggest proportion of carers, it's undeniable that policy makers need to sit up and listen. We fervently want to see women's brain health being made a priority, in line with the renewed focus on brain health in general. We will pursue any opportunity to raise this with decision makers and will continue to work closely with our colleagues at Alzheimer Scotland and Brain Health Scotland to get our message across.

"Current figures suggest that one in three women will develop some form of dementia. Unpaid carers, the majority of whom are women, prop up the creaking care system saving the government £13.1 billion per year. And the workforce of paid carers is predominantly women."

"Talking about dementia and being positive about women's brain health is not only a very valuable thing to do but it is the best way forward." – Thea Laurie, NDCAN



Visit to the Alzheimer Scotland Centre for Policy and Practice (ASCPP)

In August, NDCAN members Joanna and Marion, together with SDWG members Margaret, Kenny, and Tony were delighted to pay a visit to ASCPP at the University of the West of Scotland (UWS). The occasion was to celebrate the retirement of our esteemed friend, colleague, and mentor, Professor Debbie Tolson.

During the visit, our members were also invited to tour the on-campus DOMUS facility, which features simulated home, care, and hospital spaces, as well as reminiscence and sensory rooms. This award-winning centre is a uniquely designed space that enables students and researchers to have insight into the impact of different environments on the wellbeing of people living with dementia. While exploring this innovative facility, NDCAN members were able to engage with adaptations within the various rooms, learning more about the effect different surroundings can have.

Active Voice has maintained a close relationship with ASCPP throughout 2024, attending monthly online meetings to discuss current research and other related projects and benefiting from the insights of guest speakers on a range of relevant topics. This provides a wonderful opportunity to engage, connect, and reflect on our collaborative approach. Active Voice members regularly co-present work with ASCPP staff at these sessions, for example Kenny, Rynagh, and Barry recently presented their experiences of 'Researching Together' with Professor Louise Ritchie and Dr Laura Lebec on a Career Guidance and Dementia project.

Cementing this partnership still further, in May NDCAN members Joanna and Marion were proud to represent Active Voice at the signing of a new strategic partnership agreement with ASCPP.

Partnership working

Collaboration is key when it comes to ensuring people with dementia can live well and safely with their condition. This year, SDWG and NDCAN have supported a range of initiatives in the belief that the voice of lived experience is vital to enhance services and drive them towards excellence. We have been delighted to work alongside some inspirational partners throughout 2024.

VR Football Reminiscence Launch, Hampden Park

As one of the earliest footballing nations, Scotland's love of the sport is undeniable. Whether we have a lifelong commitment to a club or just a passing interest, there's no doubt that football has a unique ability to bring people together. It was therefore fitting that in 2024, Alzheimer Scotland's Virtual Reality Football Reminiscence experience was launched at our national stadium – the first of its kind in the UK.

Alzheimer Scotland has been a proud partner of the Scottish Football Museum for more than 15 years, delivering 'Football Memories Scotland' reminiscence projects across the country. One such project is in Glasgow where SDWG member Patricia is a regular visitor. An avid fan since the age of seven, Patricia relished the opportunity to become involved in a project with students from Abertay University to create a virtual reality (VR) football reminiscence experience. The idea was to recreate the atmosphere of a 1960s match day, capturing the sights, smells, and sounds of the time. Students reconstructed a three-part journey: travelling on a bus to the match, going through the turnstiles into the stadium, and watching the match from the terraces.



Patricia was delighted to join project partners on launch day, including Alzheimer Scotland Chief Executive Henry Simmons, and footballing legend and Alzheimer Scotland Ambassador Mark Hatley, to cut the official ribbon to open this pioneering project.

"I could see all the men wearing their caps and could even smell their cigarette smoke. It was amazing. It brought back so many memories that had been buried. Now I've got them back again, it's wonderful." – Patricia, SDWG



Golden Jubilee Hospital dementia friendly initiative

During Dementia Awareness Week 2024, SDWG member Tony Worthington was a guest at the Golden Jubilee Hospital in Clydebank for a meeting with their Dementia Lead Nurse, and Design and Equalities Lead. He went along to discuss plans to make the hospital environment as dementia friendly as possible – a project Tony has been involved with for over a year. As a person with lived experience, Tony has offered valuable advice and suggestions on possible improvements that he believes could benefit this clinical space.

His visit included a tour of the patient wards and Tony was encouraged to see that dementia clocks have already been installed in every room. He was also delighted to visit the Dementia Awareness Week information stand, further demonstrating the hospital's commitment to support those who are affected by dementia.



Allied Health Professional (AHP) Community

During 2024, we continued to support health and social care staff with their learning, encouraging good practice in the care of people with dementia. We are committed to ensuring that outcomes for those who are impacted by dementia are improved, so are very keen to help with workforce development.

An example of this in action was at an AHP learning event at Napier University, Edinburgh. Designed with a rights-based approach to dementia care in mind, and with an emphasis on the importance of lived experience, Stuart from SDWG and Frank from NDCAN were invited to share their perspectives.

Stuart urged attendees to recognise that dementia does not define a person, encouraging a holistic approach to care that focuses on preserving quality of life and individual identity. Reflecting on the positive impact his doctor has had since being diagnosed with young onset Alzheimer's disease, Stuart said, *"By treating those you will work with in your careers as individuals, supporting and encouraging them to be themselves and do what's important to them, you will...help ensure that they are not defined by their situation, but that they continue to live the best life possible."*

Frank's presentation emphasised how important AHP support can be for carers and encouraged staff to promote their resources as they can be very useful, but many remain unaware they exist. He stressed that a personalised approach to care is essential and advocated for more partnership working with those who have lived experience. And he explained that while carers can struggle with competing emotions, AHP support can be vital to help guide someone through challenging times. He said, *"There's a big opportunity for you to...pass on some of your skills to the carer so that they can reinforce and multiply the value of your work."*

All collaboration with our AHP partners is co-ordinated by close colleague, Alzheimer Scotland National AHP Consultant, Elaine Hunter. Coming together under the theme of 'Connecting People, Connecting Support', Elaine has continued to facilitate great coordination with Active Voice throughout 2024. We are delighted to assist Elaine and the AHP community in their efforts to enable people affected by dementia to have positive, fulfilling, and independent lives.

Campaign cooperation

We want to change the perception of dementia, destigmatising and breaking down barriers as we go. There's no better way to do this than by sharing our thoughts, opinions, and experiences as part of large-scale publicity events. For many years, we have been the cornerstone of Alzheimer Scotland's campaigning work and 2024 was no different. For example, during Dementia Awareness Week in May, SDWG member Margaret, and NDCAN member Elaine participated in a national promotion to raise awareness of the challenges of long-term care for the dementia community. Margaret featured in a short film about what living well with dementia means to her, with an accompanying transcript about how important it is that she keeps doing things she enjoys. Elaine shared her story through a poignant blog, focusing on her family's experience of having to pay for dementia care.



We will continue to nurture these partnerships so that the voice of lived experience is heard loud and clear, amplified through Alzheimer Scotland's communication channels in an impactful way that resonates with audiences.

Chief Executive Meetings with Henry Simmons

As well as collaboration with teams across Alzheimer Scotland, we meet regularly with Chief Executive, Henry Simmons. Henry hosts bi-monthly meetings to update us on campaigning priorities, developments in the research and drug development fields, and other relevant issues.

These get-togethers are always welcoming and interactive, with Active Voice members encouraged to share our views and perspectives. They're also a chance to reflect on what we have been doing in terms of our priorities and think about upcoming opportunities. Our input is always valued, and this process of mutual information exchange means that Active Voice is indisputably part of Alzheimer Scotland's decision-making processes. Our contributions to important subjects of the day, such as the Long Term Care Commission, Fair Dementia Care, and the emergence of new drug treatments for dementia mean that Active Voice can directly provide the leadership team with insights to help inform the charity's strategic positioning.



The Edie Adams Prize for Excellence in Dementia Information and Support Literature

For several years, Alzheimer Scotland has collaborated with the School of Psychology & Neuroscience at the University of St Andrews for their senior honours 'Psychological impact of dementia' module. As part of their learning and assessment, students are asked to produce evidence-based handbooks that contain information for people living with dementia, family members, and professional carers.



To ensure the voice of lived experience is represented, members of SDWG and NDCAN work alongside university staff to judge the top four handbooks, providing feedback relating to layout, the topic, breadth of information provided, and accessibility. Dr Maggie Ellis of the School of Psychology & Neuroscience has worked with Alzheimer Scotland for several years, with the charity providing a monetary prize as a contribution to the university's overall award to winning students. This year, Kate Matheson took the title, for her handbook – 'Navigating Sexual Intimacy and Dementia'.

She said: "I was extremely honoured to win this year's handbook prize – Dr Ellis' module really opened my eyes to the struggles faced by those with dementia and their caregivers and I was inspired by the module to begin volunteering with Alzheimer Scotland! Choosing to write about sexual intimacy was something I was initially very nervous about, but I did so as it is such an important topic that few people have explored."

Dr Maggie Ellis, senior lecturer said: "Thank you to SDWG and NDCAN members for your involvement in this year's Edie Adams Handbook prize. Our winner this year was Kate Matheson, a very deserving winner who tackled a very difficult topic in a sensitive way."

United for success – making time for teamwork

The adage, 'the whole is better than the sum of the parts', could not be more apt than when it comes to our partnership with Alzheimer Scotland colleagues. We work hand in glove with teams right across the charity, with great work achieved by everyone pulling in the same direction.

We have developed a particularly close relationship with the Communications and Campaigns team as we work together to find new and innovative ways to raise awareness of dementia and spread the word about Active Voice initiatives. We continued to join forces throughout 2024, using our priorities as guiding principles to forward plan our messaging and liaise on forthcoming themes, campaigns, and comms requirements.

We have formed an Active Voice comms subgroup which comprises Active Voice staff, members of SDWG and NDCAN, and representatives from the Communications and Campaigns team. We come together every month to share updates, generate ideas for developing content, discuss upcoming campaigns and events, and decide how Active Voice should best be represented.

This creates great synergy, and we work hard to plan and prioritise the sharing of Active Voice stories that are meaningful. After all, we know that people like to learn about other people, and with a busy schedule of events and conferences to attend, presentations to make, and public consultations to consider, it is important that we document these and share them with our audiences in the best possible way.

Sharing our experiences

We have a real opportunity to connect with others in a powerful way and by proactively sharing our experiences, thoughts, and perceptions, we can change attitudes about dementia.

For Carers, by Carers

This year, NDCAN members Ian, Joanna, Maureen, and Thea took on the challenge of updating and refreshing a suite of leaflets that was originally created back in 2016. The collection of eight booklets was designed to build resilience amongst family carers, based on personal experiences of navigating a range of challenging situations. They offered words of encouragement, with useful tools and tips to help carers negotiate difficult times, but also to enjoy life and take opportunities for self-care. They were collated after broad membership consultation, as well as extensive work with groups of carers all over Scotland.

In 2024, Active Voice members felt that although these booklets were still a valuable resource, they needed a refresh to ensure that they remain up to date and effective. Technological developments since 2016 mean that there are now digital tools that can help people live well with dementia and provide peace of mind for carers. Clinical guidelines, such as those developed by the Scottish Intercollegiate Guidelines Network have also been updated, and advances have been made in dementia care and practice – all of which needed to be reflected in a newly refreshed suite of information.



A short-life working group was created to oversee this project, with Active Voice members taking the lead in the redrafting of content and making sure that all information contained within the suite is current and of practical benefit for those it's intended to support. Both SDWG and NDCAN were delighted to launch this newly revamped resource at the SDRC Conference which fell during Carer's Week in June. If you're interested in learning more, all leaflets are available for download now at www.alzscot.org/for-carers-by-carersproject

Site seeing

In 2024, Alzheimer Scotland made the decision to redesign their website. As a primary source of information for Active Voice audiences, it is vital that the site is easily accessible, and that content is organised in the most streamlined way possible.

As part of the redesign process, and to ensure this piece of work was informed by the voice of lived experience, SDWG members Stuart and Kenny were invited to offer their perspectives on the current website's aesthetic, functionality and navigability. They were also consulted on overall content, and their opinions sought on how best to organise information for people to access at their fingertips.

Stuart and Kenny met with colleagues in Alzheimer Scotland's Communications and Campaigns team, along with the web developers to discuss what features and functionality they liked about the existing website and consider what would improve user experience – such as easy navigation and responsive design across different devices. Through completion of a user survey and 1:1 discussion, they were able to offer their thoughts on how they would like the new site to look and feel, feeding back that a strong visual impression with good use of colour, an intuitive layout and clear, direct language were most important.

"The insight and feedback from our Active Voice members was absolutely central to the redesign of our website. They helped us see the site through the eyes of those who use it most. From simplifying navigation to making content clearer and more accessible, their input shaped every stage of the process. It's a powerful reminder that the best way to understand what makes a website truly useful is to listen to the people it's there to serve." – Marri Welsh, Executive Lead, Communications and Campaigns

This input was invaluable as it offered web developers a true assessment of how well the existing website met their needs, and what improvements could be made to maximise its potential. Alzheimer Scotland looks forward to the launch of the new website this spring, which will incorporate all thoughts and suggestions offered by Active Voice members.

ADAM gets a refresh

ADAM (About Digital and Me) is an online platform created by Alzheimer Scotland that connects people living with dementia with technology aids that can make daily life a bit easier.

Co-designed with Active Voice input, members continue to be involved in ADAM's development to make sure that the platform is dementia friendly, accessible for all and that it features products that are both tested by and tailored to the needs of the dementia community.

Margaret from SDWG and Maureen from NDCAN were delighted to be asked to narrate the introductory welcome message that visitors hear when accessing the newly revamped ADAM website. To listen to their message, and explore ADAM to discover how it can help you navigate the world of technology, visit: www.meetadam.org

ADAM 
About Digital And Me



Speech and Language Therapy student sessions

In March, SDWG and NDCAN had the opportunity to meet up with members of the Allied Health Professional (AHP) community involved in Speech and Language therapy. These specialist therapists support people living with dementia and provide vital assistance with communication, language, and a range of issues associated with eating, drinking and swallowing.

The session, held in Alzheimer Scotland's Glasgow Centre enabled students training to become Speech and Language Pathologists to talk to members of our Active Voice groups about dementia, and learn more about its everyday impact. Members talked openly about how they live well with the condition, and the kinds of supports and services they access to make things a little easier. Such candid insights were valuable for the students' learning, and many noted that they will carry them forward to inform their future practice.

"I will take away from today how full someone's life can be after a dementia diagnosis."

"...The session left me inspired to work harder to achieve my qualification, as the participants expressed how crucial speech and language therapy is to dementia support."



Occupational Therapy students

Also in March, Active Voice staff facilitated a meeting with fourth year Occupational Therapy students from Queen Margaret University in Edinburgh who are currently on placement with Alzheimer Scotland. Joanna from NDCAN and Kenny from SDWG delivered insightful presentations on their personal experiences of occupational therapy, as well as taking the opportunity to highlight the importance of incorporating the voice of lived experience into daily practice.

"We would like to thank you very much for meeting with us this morning and providing us with the opportunity to speak with Joanna and Kenny. Also, thank you for giving us a wonderful presentation regarding the work of NDCAN and SDWG, it was really inspiring to see all the amazing work you are completing." - Chloe O'Neill Costello, OT Student

"It is an absolute pleasure working with the Active Voice groups. Their members directly influence the work of the allied health professionals in Scotland in a strategic, collaborative and co-ordinated way contributing to our national projects including AHP student placements, AHP self-management projects, AHP research, AHP policy and AHP post graduate education. Their ideas, guidance and ongoing collaboration is invaluable, ensuring the voice of lived experience is embedded in our national programme." - Professor Elaine Hunter, National Allied Health Professions Consultant



Sharing our experience to improve workforce knowledge

One of SDWG's and NDCAN's shared priorities for 2024 is to support workforce development and ensure that health and social care staff have the right skills to support people who are living with dementia, informed by the voice of lived experience.

In May, Stuart and Margaret from SDWG, and NDCAN member Marion, collaborated with City of Glasgow College to deliver an awareness session to social care students. They went along to share their personal experiences of dementia and answer questions from students about the realities of being impacted by the condition. Both Margaret and Stuart emphasised the importance of person-centred care, with Margaret urging the audience to always "see the person as a person", and Stuart highlighting an Alzheimer Scotland tagline, 'dementia is one thing, not everything about a person'. Stuart made a very poignant point, that his "life may have changed, but it's certainly not over".



Marion spoke about the help she received from professional carers while she cared for husband Dave, who was living with vascular dementia. She talked about the feelings of stress she experienced at that time, and the process of accepting that she needed help from professionals. Marion appealed for professional carers to "work in partnership" with families and made suggestions for the provision of both hospital and home-based care to alleviate the distress of the person living with dementia. In conclusion, she expressed gratitude for their career choice, telling her audience that they "are life savers".



Raising awareness with Dundee University medical students

The World Health Organization consistently promotes lived experience as vital for the effective design and delivery of services. We are strong advocates of this, believing that only positive things can come from our involvement in the professional development of medical and care staff.

During Dementia Awareness Week in May, Stuart from SDWG and Thea from NDCAN were delighted to meet with medical students from the University of Dundee. During the online session, they took the opportunity to share their own experiences of dementia and outline some examples of their campaigning and awareness-raising work. They also gave a direct message to the students, explaining that a person-centred approach to dementia care can have enormous impact. Both Thea and Stuart emphasised that seeing the person first, rather than the disease – and recognising carers as equal partners – is hugely beneficial. Active Voice will continue to work in this area, sharing our knowledge to inform and enhance the delivery of frontline services.

Dementia in the workplace film launch

Also in May, Active Voice members enjoyed the official launch and first public showing of the 'Dementia in the workplace' film. This awareness raising production features SDWG members Kenny, Stuart, Rynagh, and Margaret (with husband Barry) all sharing their stories of being in employment at the time of receiving a dementia diagnosis.

The film is part of a longstanding 'Career Guidance and Dementia Research Project' which SDWG members have been involved in since 2021 with our partners at the Alzheimer Scotland Centre for Policy and Practice (ASCPP). Working with a group of healthcare professionals and career guidance practitioners, Active Voice members unpicked the experiences of people who are diagnosed with dementia while still employed and explored how career guidance could support them in those circumstances. This co-produced piece of work investigated how our members navigated employment and dementia and showcased that although work may change after a diagnosis, it doesn't have to stop.



PhD student critical friend

This year, SDWG member Stuart Dougall teamed up with PhD student Molly Murray, from Alzheimer Scotland's Centre for Policy and Practice at the University of the West of Scotland. To help shape Molly's study of how people with young onset dementia navigate their environment, Stuart volunteered to offer input from a lived experience perspective.

Over the months, Stuart and Molly have developed a strong working relationship, meeting every 4-6 weeks. Stuart is only too happy to offer his support – his firsthand experience is instrumental to the project as he can impart knowledge and understanding only possible from someone who is living with dementia, making the research more genuinely informed.

Molly said: "working with Stuart has been an invaluable experience, with his unique insights enabling me to reflect on and strengthen my research."

Connecting Carers to Support

An engaging webinar on the caring experience, hosted by national Allied Health Professionals (AHPs) attracted over 120 participants in August.

Key speakers at this event were NDCAN members, Ian and Frank, who were pleased to use this platform to share their experiences as carers. Their presentations covered important issues like the challenges faced daily by carers, as well as the support they receive from the AHP community.

We place great value on sharing our unique perspectives with others, so this was a great opportunity to outline what we feel are examples of good practice from AHPs. Feedback from the webinar was overwhelmingly positive and participants expressed gratitude for Frank and Ian's contributions, saying their insights gave them inspiration to enhance their own working practices.

NHS Education for Scotland

SDWG and NDCAN readily contributes to the workforce development of employers across Scotland. An example of this in practice is our collaboration with NHS Education for Scotland (NES) to develop a new and innovative programme called, 'Fundamentals of skilled practice in dementia'. This is a 2-day in-person training programme designed to help staff who work with people who are living with dementia, and who need increasing amounts of care and support. It has been developed in response to feedback from the NHS workforce which highlighted a need for dementia training at the informed and skilled levels of the Promoting Excellence Framework.

Active Voice members teamed up with NHS staff to pool our knowledge, helping them to understand our perspective, and encouraging them to always do one thing – see the person with dementia, their family and friends, rather than just the diagnosis. We want to inspire staff to recognise our rights and understand the importance of tackling stigma and inequality.

We have been involved in this project from the start and recently participated in a poignant 'in conversation' recording. In a nod to the fact that members' perspectives can sometimes differ, we opted to create two recordings – one from the viewpoint of those living with dementia, the other from a caring perspective. We were delighted to participate in these filming sessions, which will be used to bring this vital project to life. It's very heartening to know that our thoughts and opinions can support the practical application of learning – and influence positive change in workforce knowledge, attitudes, and practice.

"Both groups have been collaborative partners with NHS Education for Scotland (NES) in developing NES 'Fundamentals of skilled practice in dementia'.

SDWG and NDCAN members are a central component in the development and delivery of this new and innovative approach to ensure dementia education is effective." – Patricia Howie, Senior Educator

Members offered two key messages to NHS staff:

"See the person, not the dementia – and please listen to us." – SDWG

"Don't keep the carer in the dark, please talk to us and let us know what's going on." – NDCAN



Engaging with decision makers – influencing policy and practice

With lived experience of health and social care provision, our Active Voice groups are perfectly positioned to engage with governments and the world of academia and research. We respond to consultations and actively engage with opportunities to have our say, all to help shape dementia policy and practice in Scotland. From the introduction of new Commissioners and guidance on the design of town centres, to changes to the Adults with Incapacity Act and the proposed right to palliative care, we are always willing to share our experiences to improve the lives of those impacted by dementia.

Student Research Programme

The Alzheimer Scotland Student Research Programme supports the next generation of dementia and brain health research by funding studentships at institutions across Scotland. The programme aims to fund at least one Masters level placement every year and is particularly interested in areas that are under-served and/or encompass innovative approaches to research.

At the heart of the funding process is the voice of lived experience. Active Voice members are invited to influence the entire journey – from selecting priority topics for study, to providing input on applications, and forming part of the selection panel to conduct interview with applicants. This means that Active Voice has a real opportunity to shape the direction of dementia research in Scotland.

The programme has funded three studentships over so far, with the candidate selection panel comprising members of both SDWG and NDCAN supported by academics who have funding experience.

Successful applicants benefit from continued close collaboration with Active Voice, meaning that their research journey is guided by people with lived experience. They regularly update us with any findings and share their progress with wider audiences, including presenting at conferences and other high-profile events – enabling them to network with world-leading researchers affiliated with Alzheimer Scotland.

"The Active Voice contribution to this innovative research programme is invaluable, not only in shaping the direction of the research but in providing a unique experience for early career researchers. The opportunities to link with the expertise of lived experience provides students with new insights and ideas, with feedback that they feel inspired and encouraged. This experience will be carried throughout their careers, placing people with lived experience at the heart of research". – Alison McKean, Executive Lead for Brain Health and Research



Long-Term Care Commission report launch

In May, representatives from SDWG and NDCAN were delighted to attend the launch of a report which provides recommendations for the future of long-term care in Scotland.

The report followed the work of a Commission established by Alzheimer Scotland and led by the former First Minister of Scotland (and Alzheimer Scotland Ambassador), Henry McLeish. The report identifies several key themes. These include the need for a strategic plan for commissioning for long term care arrangements in Scotland; engaging in broad and honest public dialogue about the costs of care, and how it is paid for; exploring new approaches for paying for long term care; tackling the workforce crisis; and ending the unfair treatment of people with advanced dementia. Members of both SDWG and NDCAN have been key members of the Commission from the outset and have offered crucial contributions to the content of the report.

In recognition of their involvement, Kenny from SDWG and Bill from NDCAN were invited to give a presentation at this well-attended event, with both outlining what long-term care means to them, and why the recommendations of the new report are so important.

“The participation and contribution of the members of SDWG and NDCAN, alongside the public engagement events they supported to inform the work of Alzheimer Scotland’s Long Term Care Commission is invaluable. We are hugely grateful for their insight, with this critical report and campaign seeking to influence positive change for the future of long term care provision in Scotland.” – Jim Pearson, Deputy Chief Executive, Alzheimer Scotland



Drug developments

2024 was an important milestone in the Alzheimer’s drug development pipeline. For the first time, clinical trials have proven that Alzheimer’s disease can be slowed using drugs and in 2024, we saw the first ever disease-modifying treatments approved for use in the UK by the Medicines and Healthcare Products Regulatory Agency (MHRA). Unfortunately, a decision by the National Institute for Health and Care Excellence (NICE) has deemed that emerging drugs lecanemab and donanemab are not cost-effective for use on the NHS.

Alzheimer Scotland is committed to advocating for the Scottish Medicines Consortium (SMC) to reconsider NICE’s interim decision. Active Voice supports this stance, believing that the SMC should assess the benefits of these drugs not only from a financial standpoint, but by considering the profound positive impact they could have on the quality of life of people living with Alzheimer’s disease.

Throughout the year, both SDWG and NDCAN have engaged in compelling discussions about this with Alzheimer Scotland’s leadership team. As a result, we have unanimously agreed to support their position to influence the SMC to make lecanemab available on the NHS. In a range of meetings and consultations, Active Voice members have repeatedly stated that the issue stretches beyond the monetary cost associated with these new treatments. Fundamentally, it concerns the human rights of individuals with an early diagnosis of Alzheimer’s disease, ensuring they receive the necessary treatment in a timely manner.



National Care Service

Throughout 2024, members of SDWG and NDCAN continued to engage on the Scottish Government's plans to deliver a new National Care Service. As well as participating in the National Care Service Forum, we have also shared our views as part of Alzheimer Scotland's dementia-specific engagement, focusing on supporting people with lived experience to get involved with boards and panels that oversee and hold decision-makers to account.

There was also an opportunity to meet with Maree Todd MSP, Minister for Social Care, Mental Wellbeing and Sport, to share our opinions on the need for social care reform and discuss how the National Care Service could contribute to improving the experiences of people with dementia and their carers. We will continue to raise awareness of the challenges faced by the dementia community and campaign for the reforms we believe are needed to bring meaningful change to our lives.

Human Rights and Public Policy Advisory Board

Another route for SDWG and NDCAN members to share our voice is through Alzheimer Scotland's Human Rights and Public Policy Advisory Board. This is a committee that leads on policy and direction, providing advice and expertise to support and inform the policy work of Alzheimer Scotland, with a particular focus on the protection of rights and the work of the National Dementia Advisor Service.

Both SDWG and NDCAN are represented on this Board, regularly sharing our thoughts and opinions to help shape Alzheimer Scotland's position on policy matters, and abiding by the principle, 'nothing about us, without us'. This kind of involvement in the development of practice tools means that our values, as those who are experts through experience, are incorporated.

Carer's Parliament

In November, NDCAN members Elaine Deehan and Gillian Muir travelled to the COSLA Conference Centre in Edinburgh for the annual sitting of the Carer's Parliament. This year's event was organised by Carers Scotland on behalf of the Scottish Government and was chaired by Professor Ian Welsh OBE, former Chief Executive of the Health and Social Care Alliance Scotland. It was a hybrid session, welcoming over 120 delegates both in-person and virtually and offered the opportunity for unpaid carers to raise their concerns and questions directly with local and national government.

A prevalent thread for the day was health, with many carers expressing concern that the responsibility of offering full-time care is having a negative impact on their physical and mental health. There was also a sense of frustration at the lack of progress made to establish a National Care Service. Elaine and Gillian made sure the voice of dementia carers was heard loud and clear on this front, expressing our deep disappointment that it is no further forward. They were able to communicate this directly to Maree Todd, Minister for Social Care, Mental Wellbeing and Sport, and Councillor Paul Kelly, COSLA spokesperson for Health and Social Care. They also had the opportunity to participate in a series of discussion groups focused on benefit entitlement and financial security for unpaid carers.

The event offered great networking opportunities, enabling Elaine and Gillian to speak on our behalf about the realities of providing unpaid care, connect with peers, and exchange ideas for practice improvement.



Reducing stress and distress in practice

Over the past year, SDWG and NDCAN have worked closely with Healthcare Improvement Scotland (HIS), supporting their Focus on Dementia team to develop a new stress and distress reduction programme. This is to help people who are living with dementia cope better when accessing inpatient and residential care services.

When situations of stress and distress occur, it is important that people have a sense of control and can develop strategies to cope. Understanding how this can impact dementia is important to anyone who provides care – knowing how to respond helps to ensure that the wellbeing and rights of the affected person are upheld. In partnership with Active Voice, HIS has developed two separate tools to help frontline teams who support people experiencing stress or distress in clinical or residential care environments. The first is a form of self-evaluation, used by staff to assess the effectiveness of their practice and identify areas for improvement. The second is a person-centred assessment to help staff understand possible underlying causes and enact a system of appropriate care.

Central to the development of these tools is the voice of lived experience. Practitioners have welcomed the input of SDWG and NDCAN throughout – their insight has been instrumental and will ensure that when the programme is rolled out, it will help staff manage the symptoms of stress and distress in the right way.

Focus on dementia: A care coordination programme for post diagnostic support

Post diagnostic support (PDS) is a service that people with dementia in Scotland are entitled to following their diagnosis. This support is delivered by a PDS worker, often called a Dementia Link Worker, who is allocated to the person for at least one year.

PDS for people newly diagnosed with dementia has been a national commitment in the Dementia Strategy for Scotland since 2013. Over the past year, Active Voice has collaborated with Health Improvement Scotland to capture lived experience views on how it is delivered. Members have participated in local engagement sessions and events hosted by HIS to share our personal experiences of PDS, helping to paint a picture of its benefits along with some suggestions for improvement.

“Being able to meet with SDWG and NDCAN gives our work greater credibility, keeps us grounded on what needs to be done and why it is so important to keep working to make things better. Hearing first hand experiences of where support has been good makes it all worthwhile but equally hearing where things are still not good in many areas is immensely sobering but galvanising, making our roles and the need to get on with it feel even more essential.”

We greatly appreciate being able to connect with both groups, thank you.”



Farewell and thank you

Active Voice embraces the opportunity to serve on Alzheimer Scotland's Board of Trustees, and since 2021, Geoff Orry from SDWG and Thea Laurie from NDCAN have served as elected members. This has enabled us to stay closely aligned with the charity's strategic direction and provide valuable lived experience perspectives.

In 2024, after a remarkable three years of service, Geoff and Thea made the decision to take a well-earned rest and step down. We would like to take this opportunity to express our sincere thanks for their dedication and exceptional commitment over the years. Acting as a Trustee is a significant volunteering responsibility, and Geoff and Thea always accepted their duties with great purpose and resolve.

They are judicious stewards of Active Voice and their input to the Board will be greatly missed. We look forward to staying in touch for years to come as they continue their membership of SDWG and NDCAN.

Following their departure, we are delighted to announce that Stuart Dougall has stepped into the role, joining NDCAN colleague Joanna Boddy on the Board. We know that Stuart will pick up the reins to provide help, advice, and insight to Board members, working alongside Joanna to represent Active Voice over the coming years. Good luck Stuart!

"It was such an honour and privilege to be appointed to the Board of Trustees and to follow in the footsteps of such a gentleman and stalwart as Geoff Orry. I will endeavour to carry on Geoff's work and represent people with dementia."

"I want to express my heartfelt gratitude to my colleagues on the Board for their warm welcome, which made the process far less daunting. A special thanks goes to my mentor, Joanna Boddy, and to Julie Drummond for designing such an excellent induction programme." – Stuart Dougall, SDWG

"As Thea steps down from her role on the Alzheimer Scotland Board, I would like to thank her for all her contributions to the work of the Board. Thea is a great advocate for the voices of carers and people with lived experience. Her interest in women's health has ensured that this issue is high on the agenda. She is also a great ambassador for the Alzheimer Scotland tartan! I will miss having a fellow NDCAN member to share discussions with but I know that she now plans to focus on NDCAN so we will continue to benefit from her knowledge, energy and commitment. So, it is Au revoir and not Goodbye, Thea!" – Joanna Boddy, NDCAN





**Alzheimer
Scotland**
Action on Dementia

**Prevent.
Care.
Cure.**

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