

Active Voice

Spring Newsletter 2025

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Hello and welcome to our spring 2025 newsletter

We are excited to share the latest updates from the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) in our spring newsletter.

This edition features inspiring stories of our members' dedication and hard work. I'm sure you will agree that their ongoing efforts are truly making a positive impact and helping to improve care and support for people living with dementia, their families and carers.

Join us in celebrating the commitment of both our campaigning groups and discover what they have been working on over the past few months. We hope you find this as inspiring to read as it was for us to put together.

Celebrating Inspiration:

Tony Worthington Awarded the UWS Celebration Medal

The Alzheimer Scotland Centre for Policy and Practice (ASCPP), a collaborative partnership between the University of the West of Scotland (UWS) and Alzheimer Scotland, is dedicated to advancing excellence in dementia education and research. Each year, ASCPP proudly awards the UWS Celebration Medal to individuals who have inspired change and positively impacted the way we and others respond to dementia.



Tony with the
Active Voice staff team

This year, the Centre honoured Tony Worthington, who has been a dedicated member of the Scottish Dementia Working Group (SDWG) since 2018, shortly after his own diagnosis of dementia. The award was presented to Tony during a special celebration lecture event at UWS in Paisley in April. The ASCPP team has been inspired by Tony and his wife, Angela, for their unwavering commitment to enhancing the lives of people living with dementia and their family carers. They believe that Tony truly embodies the theme of this year's event: 'Living a Purposeful Life with Dementia'.

Reflecting on Tony's remarkable journey, Professor Louise Ritchie, Director of the ASCPP Manager said:

"Tony has been influential in both the direction of our Centre and the wider landscape for support of people affected by dementia. His contributions are always thoughtful, impactful, and driven by a deep commitment to improving the lives of people with dementia at a political and societal level. Tony's dedication continues to inspire all of us at the ASCPP."

Tony's career spans from his early days at the London School of Economics and work at a Kent borstal, which shaped his dedication to social justice, to his tenure as MP for Clydebank and Milngavie. His influential work included promoting peace in Northern Ireland, chairing the International Development Select Committee, and championing local redevelopment efforts. Since his diagnosis, Tony's dedication has continued and he has become a passionate advocate for people who are living with dementia. He is an inspiration to colleagues at SDWG, NDCAN, Alzheimer Scotland and ASCPP, and we look forward to working with him for years to come.



Tony with
Henry Simmons

Henry Simmons, Alzheimer Scotland's Chief Executive said: "Tony's activism and passion truly deserve this recognition."

Colleagues from SDWG and the National Dementia Carers Action Network (NDCAN) also praised his positivity, insights, and commitment to living well with dementia.

"Tony's life skills in teaching and politics help to give NDCAN different understandings and perspectives. Tony deserves this award for teaching us all how to live well with dementia."
- Elaine Deehan, NDCAN

Upon receiving the award, Tony said: "This recognition is not just for me, but for everyone I have had the privilege of working alongside in this vital field."

Undoubtedly, Tony's resolute commitment to campaigning, raising awareness, and living purposefully with dementia has earned him the UWS Celebration Medal. This achievement is perhaps best captured in the words of Kenny Moffat from SDWG:

"Tony is without doubt an inspirational individual who cares deeply about other people within the dementia community and brings a lifetime of public service to the table at every opportunity. I feel extremely privileged to class him as a friend and colleague and offer my sincere congratulations on being given this award - which is certainly much deserved."

Tony's recognition with the UWS Celebration Medal highlights his extraordinary dedication to raising awareness, and campaigning and for people living with dementia.

In the words of Debbie Tolson Inaugural ASCPP Director, "He has challenged the ASCPP team to embrace new understandings of life with dementia, to see policy gaps and solutions. Tony's influence is an important part of the ASCPP story, he is a truly inspiring person."

'Travelling with dementia' booklet

Active Voice members actively share their personal experiences to help those who are impacted by dementia. By conveying a wide range of hints, tips, observations, and insights, members can help to shape services that are relevant and effective for the dementia community. It was with this in mind that a short life working group was established to review and refresh a 2015 information leaflet that focused on travelling with dementia.

Over several weeks, members of SDWG and NDCAN came together to discuss updates to the leaflet they felt were important. This is an empowering resource designed to support those living with dementia who are planning travel, and so it was important to ensure that it still provided the most effective support and guidance. As with the previous edition, updates to this version were led by SDWG and NDCAN, whose lived experience helped shape the content to reflect everyday challenges and offer practical solutions, advice and signposting for people with dementia and their carers.

The refresh was made possible thanks to Occupational Therapy students, Emma and Hannah, who we were fortunate to have join Active Voice on placement through Professor Elaine Hunter, AHP Consultant. They facilitated meetings of the short life working group and supported members to capture and present their insights in a clear and accessible format, creating a resource that is both meaningful and easy to use.

Whether you are navigating public transport, going to an appointment or planning a day trip this summer, the booklet offers helpful tips to make travelling a calmer experience. We hope it will be a reassuring companion wherever your journey takes you.

"I have been delighted to assist Emma and Hannah with their work in refreshing the Active Voice Travelling with dementia booklet. Working alongside Active Voice colleagues gave us an opportunity to consider all that we felt was required in the booklet which I am confident will prove to be a very useful resource."

- Kenny Moffat, SDWG

"It was a very enjoyable experience to work with SDWG members and fellow NDCAN members on updating the Travelling with dementia booklet. Travel plays such an important part in our lives - be it for work, appointments or keeping an active social life. The booklet provides useful tips and strategies for coping with dementia in these situations. It is vitally important for people with dementia to lead as active a life as possible. I hope you find the booklet helps you both before and whilst travelling to enjoy getting from A to B as much as possible."

- Frank Stephen, NDCAN

Active Voice at Glasgow's Young Onset support evening

We were delighted to accept an invitation to join our Glasgow Dementia Advisors, Kevin and Iain, at their recent 'Information and Social Evening' on a sunny night on 13 May. Even with the lovely weather tempting folks to spend time outdoors, the event at our Glasgow Dementia Resource Centre saw a fantastic turnout, with everyone keen to connect, share their stories, and learn more about the support available after a diagnosis. It really was inspiring to see such enthusiasm and community spirit in action.

Margaret from SDWG, and Marion from NDCAN were delighted to present at this event which was organised specifically for people under 65 who are currently receiving post-diagnostic support, and their carers or family members.

Margaret shared her inspiring journey after being diagnosed with young onset dementia at just 51 years old. She spoke candidly about the challenges she faced but also about the support she received from Alzheimer Scotland and in particular, the community groups she attended, which transformed her outlook on her diagnosis. Now a passionate campaigner, Margaret spoke about her ongoing work with SDWG to raise awareness, influence decision makers, and share her story at every opportunity. Her final message was a powerful reminder for everyone living with dementia: live actively, challenge yourself, and always remember that dementia does not define who you are.



Margaret & Marion

"Thankfully my situation began to change for the better when I discovered Alzheimer Scotland. Contacting them was a decision that would completely change my outlook. I found people who truly understood my experience and were ready to provide support and guidance."

- Margaret SDWG

Marion then took the spotlight. As a former carer for her husband who lived with Vascular dementia, she shared her story about some of the complexities of her caring role and the roller coaster of emotions she experienced. However, she went on to emphasise that every journey with dementia is unique and encouraged everyone to accept support when needed. Marion specifically highlighted the incredible help she received from her local Alzheimer Dementia Advisor before concluding her presentation by sharing insights of her campaigning and awareness raising work with NDCAN.

"The support I received from my local Dementia Advisor was an absolute lifeline for me – she was there for me throughout my caring journey, and always made time for me whenever I needed to speak with someone." - Marion NDCAN

Following the presentations, Margaret and Marion dedicated the remainder of the evening to socialising and offering peer support to attendees. Overall, the event was a fantastic success and highlighted how SDWG and NDCAN can help make a meaningful difference by encouraging open conversations, sharing personal stories, and promoting active participation. This sentiment was shared by Kevin Black, Dementia Advisor and event organiser:

"Margaret and Marion gave very personal and powerful accounts of their journey with dementia and the parts that they have played in Active Voice, this helped our audience see that although there will be challenges, you can still live well, and this was so important for our group to hear." – Kevin Black

Partners in Research

The 12 May saw the re-launch of the Brain Tissue Bank, funded by Alzheimer Scotland. SDWG members Rynagh Flynn and Keith Guy attended the launch event at The Spires-Jones Lab at the University of Edinburgh, alongside Dr Tom Russ, Director of the Alzheimer Scotland Dementia Research Centre, Professor Tara Spires Jones, Director of the Centre for Brain Sciences, current PHD Students, Alzheimer Scotland Helpline staff team, and Chief Executive Henry Simmons to name but a few.

This special event began with a talk and tour of the research lab at the university, during which attendees learnt about the process of brain tissue donation and the exciting research that is carried out at the laboratory. Brain tissue donation is a vital step towards finding better treatments for the diseases that cause dementia. The Alzheimer Scotland Brain Tissue Bank can accept donations of brain tissue from people diagnosed with dementia to assist in research now and in the future. SDWG member Rynagh said:



Brain Tissue Bank

"Attending this event was memorable for the gathering of eminent folk that were there for the Brain Tissue Bank re-launch, funded by Alzheimer Scotland. The purpose is to encourage more people to include brain tissue donation on their death so that solutions to the disease can be found. We met several of the lab personnel who are working on different aspects of dementia research. An awesome example we were shown is the work being done to track Tau, its movement, partnerships with other molecules and the consequences this has for the brain. It's always a great privilege and a delight to visit the lab. I'm happy to speak about the Brain Tissue Bank, signing up to it was something I did early on and the progress that has been made over a relatively short time is amazing."

Scottish Dementia Research Consortium Conference

This two-day event at the Royal College of Physicians in Edinburgh celebrated a range of Scottish dementia research, with the focus on busting research myths and challenging some of the taboos that still exist. There were keynote speeches from world-leading researchers and presentations from early career researchers as well as people with lived experience, including SDWG and NDCAN members on both days.

Challenging Taboos and Busting Myths

Day one

SDWG Member Kenny Moffat, along with NDCAN colleagues Joanna Boddy and Elaine Deehan, shared their experiences of being part of the Alzheimer Scotland Student Research Programme and introduced the first three recipients of the award – Kelly Kelly, Sarah-Jayne Hamilton and Katie Robertson. Joanna and Elaine were in the auditorium, each speaking about the Masters opportunity and how the participant selection panel was led by people with lived experience – from setting the research theme, to sifting applications, and contributing to the interview process.

Even though Kenny wasn't able to attend in person, he joined us virtually with a perfectly-timed recording which shared his views and experiences of this unique research programme. Thank you, Kenny!



SDRC Conference presentations

Day two

We kicked off with an informative presentation from Dr Tom Russ which challenged and explained the world of acronyms within the research field.

Active Voice then took to the floor, with SDWG members Rynagh Flynn and Stuart Dougall and NDCAN member Marion Ritchie presenting alongside Alzheimer Scotland's Executive Lead for Research Alison McKean. Rynagh, Stuart and Marion shared personal reflections on participating in research, and explained why they support the work and priorities of brain health and research.

"Dementia can often leave people feeling powerless- participating in research offers a way to reclaim control and become part of the solution. Every voice, every story and every participant bring us closer to the ultimate goal – a cure and a brighter future."
– Stuart Dougall, SDWG

"The SDRC conference was a wonderful opportunity to hear from researchers about ongoing developments in finding the causes of dementia and to hear about progress in the support and care for those with the disease. Just one of the fascinating things I learned was that dementia has been known about for a couple of thousand years BCE. The Egyptians even had hieroglyphs to describe it, and they weren't the only ones aware of the disease. Dementia was also known about in other civilisations around the world hundreds, even thousands of years before Alois Alzheimer came on the scene."
– Rynagh Flynn, SDWG



SDRC Conference



During the afternoon session, SDRC Committee representatives Thea Laurie (NDCAN) and Tommy McLean (SDWG) joined Dr Jodi Watt of the University of Glasgow to speak personally on the subject of Taboo: Guidance on inclusivity and language.

This theme considered the importance of seeing the individual first, rather than the disease that affects them.

"What took me by surprise following my diagnosis was the words I began to hear and notice around me. For example, that people living with dementia 'suffer', or phrases like 'fading away'. I soon realised just how this kind of language paints a picture of a person who is helpless and no longer the person they once were." – Tommy Mclean, SDWG

The conference also enabled us to host the Active Voice information stand alongside colleagues from Join Dementia Research, About Dementia and Brain Health Scotland, as well as offering networking opportunities with fellow delegates and presenters.

"In Active Voice, we share our stories and experiences in the hope of making a difference, and we enjoy participating in projects which are close to our hearts. The world needs dementia research – and dementia research needs you – the researchers of this generation and to encourage future generations. I hope you will continue to share your research and collaborate with others all over the world."
– Marion Ritchie, NDCAN

Staying focused: SDWG & NDCAN Business Meetings

Members of SDWG and NDCAN, committed to their dedicated campaigning work, regularly come together for their respective 'Business Meetings' which are held every two months. These sessions are a platform to review how recent activities have aligned with their priorities and focus areas; and to plan upcoming opportunities. Over the past two months, both groups have held their Business Meetings at the Glasgow Brain Health and Dementia Resource Centre and virtually through the Teams online platform.

A significant topic on the agenda for both groups has been the development and introduction of a new 'Progress and Impact' document. This will serve as a progress report to help both groups measure how their campaigning and awareness-raising activities are making a difference. It's about answering the important 'So what?' question, or in other words, how are their efforts having an impact? During recent meetings, members of both groups have reviewed the design of this document, discussing its layout and wording to make sure it truly reflects their goals. We're happy to report that after much consideration, the designs have now been finalised and the groups are ready to begin filling them with interesting content.

It's always inspiring to see the members working so collaboratively and thoughtfully to monitor their progress. This dedication helps ensure their campaigns are effective and impactful, bringing us all closer to the positive change they envision.



International voices

Our representatives at the European Working Groups for People with Dementia and for Carers, Margaret McCallion (SDWG) and Barry Northedge (NDCAN) both step down from their roles next month after 5 and 3 years respectively.

These groups, hosted within Alzheimer Europe, meet regularly online and in person with colleagues from other Alzheimer Associations across Europe.

Margaret and Barry's participation has ensured that the voices and views of people in Scotland are reflected not only here at home, but also in the priorities and campaigns across Europe.



Barry & Margaret

We are so grateful for the time, commitment and representation that they have both given over the years, and we are extremely proud of the impact they have made. Margaret and Barry have both spoken at annual Alzheimer Europe Conferences and had leading roles when the conference was hosted in Helsinki in 2023.

Another big thank you must go to Barry's wife, SDWG member and our friend – Margaret Northedge. Margaret has supported her husband's role, sitting through long meetings and enduring sometimes lengthy journeys travelling from Drumnadrochit in the Highlands to meetings in Brussels and Luxembourg, Margaret soon became an adopted member by everyone at Alzheimer Europe!

Thank you from us all.



Nominations for two new representatives from our Active Voice groups have now been put forward by Alzheimer Scotland. These will be announced in the coming weeks.

Want to know more about the Active Voice at Alzheimer Scotland?

The Active Voice of people living with dementia and their carers is about upholding rights and driving change. We support people with lived experience to help influence and shape policy practice – Your Voice Matters! You don't have to be politically minded or need any qualifications to get involved. The only important thing is you know what issues affect you as a person whose life has been affected by dementia. If you would like further information or an informal chat with a member of the Active Team, please email us at: activevoice@alzscot.org

Active Voice

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