

# Active Voice

## Summer Newsletter 2024

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# Hello and welcome to our summer 2024 newsletter

We're thrilled to share the latest news from the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) in our summer newsletter!

In this edition, covering the months of July and August, you'll find inspiring examples of our members' commitment, and hard work – their ongoing efforts really are making a positive difference in improving care and support for those living with dementia and their carers.

Join us as we celebrate the dedication of both our campaigning groups and highlight what they've been up to over the past couple of months. We hope you enjoy reading and feel as inspired as we do!

## Meeting with Brain Health Scotland

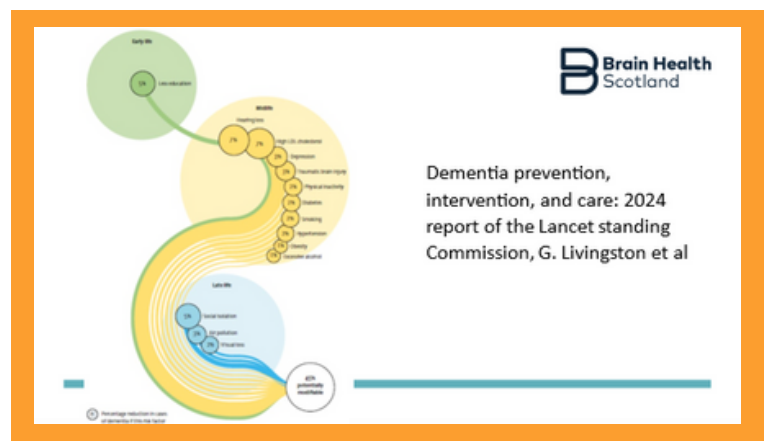
Over the past year or so, Brain Health and Research have become significant topics, whilst gaining considerable attention in the media. It therefore comes as no surprise that during this time, they have also emerged as priority areas for both the SDWG and NDCAN groups.

Despite the heavy rain in Glasgow, there was a large and enthusiastic turnout, both in person and online, as Hugh Masters, Brain Health Policy Consultant from Alzheimer Scotland, engaged with members.

Attendees were updated on the Brain Health Clinic in Aberdeen, which opened its doors in December 2023. They learned about the positive impact the clinic has had, allowing individuals to reach out directly with their concerns and receive personal consultations with the Centre Manager. Hugh went on to explain that the clinic features a psychiatrist available one day a week and a nurse on-site for three days a week. Funding for the Brain Health Clinic comes from Alzheimer Scotland, Public Health, and the Scottish Government.

There were also discussions about language, particularly regarding prevention and the importance of avoiding negative language that assigns blame. The focus was then placed on discussing risks, reduction strategies, prevention, and modifiable risk factors. Hugh expressed a strong interest in hearing the SDWG & NDCAN members' perspectives on this topic.

Hugh later shared the findings of the [Lancet Report 2024](#), which was published prior to the meeting. The report highlights the latest driving force in evidence that now identifies 14 potentially modifiable risk factors throughout early, mid, and later life.



Brain Health Meeting

## Business Meetings for group members

In addition to their ongoing campaigning work, members of SDWG and NDCAN conduct regular 'Business Meetings'. These bi-monthly meetings not only allow the groups an opportunity to reflect on what they have been doing in terms of their priorities, but also to discuss upcoming opportunities. Over the summer months, both groups held their individual Business Meetings at Oxford Street in Glasgow.

### SDWG Business Meeting – July 2024

Over twenty dedicated members attended this meeting to work their way through a busy agenda which prompted some compelling discussions.

One of the key topics was a proposal from the 'Focus on Dementia' team at Healthcare Improvement Scotland. They are working on a new improvement programme aimed at reducing stress and distress for people living with dementia in residential settings, and they requested the group's involvement. The members unanimously agreed to support this initiative, once again showing their commitment to enhancing the quality of life for those impacted by dementia.



SDWG Business Meeting

### NDCAN Business Meeting – August 2024

This recent NDCAN Business Meeting once again demonstrated the NDCAN members' collaboration, enthusiasm, and shared commitment to making a positive difference to the lives of carers of those affected by dementia.



NDCAN Business Meeting

The meeting kicked off with updates from members about various initiatives they are currently engaged in. Highlights included updates on Alzheimer Scotland's MRes program, the Human Rights & Public Policy Advisory Group, and the European Dementia Carers Working Group. There was also an insightful recap of a recent workshop focused on Supported Decision-Making.

Following the updates, the group discussed their involvement in upcoming conferences hosted by Alzheimer Scotland and Alzheimer Europe. It's always an honour for NDCAN members to take the stage at these prestigious events, ensuring that the voices of carers resonate strongly.

In a new development, members unanimously agreed to establish a Local Engagement Sub-Group. This innovative initiative aims to foster meaningful connections with a diverse range of carers, and former carers of people living with dementia across all localities in the country.

The meeting concluded with a lengthy discussion about the role played by the Active Voice staff team. Members expressed their appreciation for the support and dedication the team provides, reinforcing their confidence in the staff efforts to assist the group.

## Proposed CPD Course on Mental Capacity, Human Rights Law

Representatives from SDWG and NDCAN participated in an online meeting hosted by The Centre for Mental Health Practice, Policy and Law Research. The focus of the discussion was the proposed creation of a 'Continuous Professional Development' (CPD) program centred on mental health, mental capacity, human rights law, and associated practices. Following an overview of the proposal, the group members were invited to share their thoughts on how best to structure and design this new training initiative.

The program will be aimed at individuals working in the mental health field who are subject to, or supported by, law and practice.

In particular, the training will aim to:

- Improve the use of existing legislation and prepare for future legislative, policy, and practice changes following the Scottish Mental Health Law Review and the resulting Scottish Government Programme of Reform for mental health and capacity law.
- Reinforce the principles underpinning a human rights-based approaches (including CRPD), to the Adults with Incapacity (Scotland) Act 2000 (AWI), the Mental Health (Care and Treatment) (Scotland) Act 2003 (MHA), and the Adult Support and Protection (Scotland) Act 2007 (ASP).

### Some topics for training that were discussed include:

- o An introduction to how the law and human rights work
- o Medical treatment and healthcare
- o Personal decision-making and support for decision-making
- o Rights restrictions (e.g., detention, restraint, forcible treatment, enforcement of the Adults with Incapacity (Scotland) Act 2000)
- o Accountability and securing rights to support
- o Assessing capacity and 'significantly impaired decision-making ability' (SIDMA)
- o Carers' rights
- o Mental health and criminal justice



Members shared their views on how incorporating the lived experiences of people with dementia and their carers would be very beneficial to individuals attending the CPD training. Challenging stigma and assumptions are key to this work, especially as many people with a diagnosis of dementia do not receive reviews or follow-up appointments following their diagnosis. One main outcome from this meeting was the recognition that discussions around mental health law, capacity, and protection typically arise only when a crisis occurs. Therefore, this training would not only benefit the professional workforce but subsequently, it would help support people living with dementia, and their families and carers.

The program is being developed by Edinburgh Napier University who have collaborated with SDWG and NDCAN in previous projects. Therefore, members of both groups were very enthusiastic to participate in this new initiative, especially as it aligns with their 'workforce development' priorities.

## SDWG and Alzheimer Scotland Bi-Monthly Update Meeting:

### Discussion on lecanemab

On Thursday 22 August, the Scottish Dementia Working Group (SDWG) met with Henry Simmons, the Chief Executive of Alzheimer Scotland, for their bi-monthly catch-up. These meetings serve as an appropriate platform for the group to be updated on Alzheimer Scotland's latest priorities while sharing updates on their own ongoing campaigning work.

By sheer coincidence, the meeting coincided with a breaking news story that the UK's medicines regulator, the MHRA, has approved the new Alzheimer's treatment, lecanemab, for use across the UK. However, Henry warned that the National Institute for Health and Care Excellence (NICE) has issued a provisional decision stating that lecanemab is not yet considered cost-effective for the National Health Service (NHS) in England and Wales. This means that, for the time being, the drug will only be accessible through private channels.

This news turned out to be the focus of the SDWG update meeting. Henry articulated Alzheimer Scotland's position on the matter, emphasising the organisation's commitment to advocating for the Scottish Medicines Consortium (SMC) to reconsider NICE's interim recommendation. The Consortium will be encouraged to assess the benefits of lecanemab not just from a financial standpoint, but by considering the profound positive impact it could have on the quality of life for people living with Alzheimer's disease.

The SDWG engaged in a compelling discussion with Henry and unanimously agreed to support Alzheimer Scotland's position in influencing the SMC to make lecanemab available via the NHS. The members articulated that the issue goes beyond the monetary cost of this new treatment - it fundamentally concerns the human rights of individuals with an early diagnosis of Alzheimer's disease, ensuring they receive the necessary treatment.

Later the same day, we were delighted to hear SDWG member Stuart express his views on BBC Radio Scotland. His perspective on this news story was well received by the other SDWG members and further emphasised their position on this ongoing concern.

**"We call on the Scottish Medicines Consortium to not follow the interim recommendation by NICE and to instead measure the benefits of this new treatment in terms of the enormous impact it could have on the quality of life for people with Alzheimer's. We must take this step forward and not hold back in any way." - Henry Simmons**

#### Breaking news:

**Alzheimer's disease drug lecanemab approved by MHRA for use in the UK, but unlikely to be available for use on the NHS.**



SDWG meeting  
with Henry Simmons

## Local Engagement at the core of SDWG

Members of SDWG recognise the significance of maintaining strong ties with local communities. In relation to this ideology, we are pleased to share a recent positive example that showcases our members' dedication to staying connected with local support and services.

During August, SDWG members Tony and Tommy paid a visit to the Alzheimer Scotland Dementia Resource Centre in Bearsden. This fantastic facility plays a crucial role in supporting individuals living with dementia and their families throughout East Dunbartonshire. During the visit, Tony and Tommy were encouraged to see the range of support and resources available to help improve the lives of those affected by this condition.



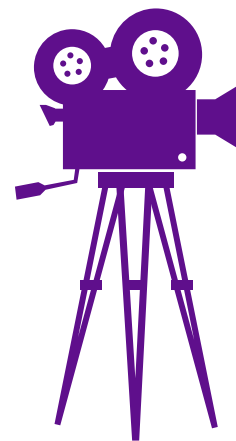
However, what left a lasting impression on them was the Centre's inviting, dementia-friendly and thoughtfully designed environment. Inspired by the warm ambience of the Bearsden Centre, the visit provided an excellent setting for Tony and Tommy to discuss upcoming SDWG initiatives aimed at raising awareness of dementia.

## Recording day: group members collaborate on two innovative projects

Involving the perspectives of those with lived experience is crucial, and the members of SDWG and NDCAN are at the forefront of this philosophy. Their active participation in a range of initiatives brings together a whole range of expertise and insights, which is so beneficial to the projects they champion.

Two significant initiatives that SDWG and NDCAN members have been actively engaged with from the beginning are the 'NHS Education for Scotland (NES) New to Skilled Educational Program', and Alzheimer Scotland's innovative ADAM online portal.

Recently, members from both groups dedicated a productive day to recording engaging content as part of their commitment to both these important projects



### **NHS Education for Scotland (NES): New to Skilled Educational Programme**

This program 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. Members of both campaigning groups have been involved in this project from the outset and recently participated in a poignant 'in conversation' recording, which will serve as an integral part of the training program.

Acknowledging that members' perspectives can sometimes differ, the groups collaboratively opted to create two separate recordings, ensuring that all voices were heard.

The film recordings offered members the chance to share their experiences of living with dementia or caring for someone with the condition, discussing both positive experiences and negative impacts. They emphasised what is important for the health and social care workforce to know, and moreover, how they can contribute to making a positive difference.

Once edited, the recording will help 'bring to life' this vital education resource aimed at training the NHS professionals with the knowledge and understanding necessary to foster compassionate care and support.



### Key messages to NHS staff

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

**- SDWG**

**"Don't keep the carer in the dark, talk to us and take time to explain what's going on."**

**- NDCAN**

### Updating ADAM

ADAM (About Digital and Me) is an online platform created by Alzheimer Scotland which has been designed to support individuals living with dementia by connecting them with the right technology tools at the right moment.

ADAM has been co-designed with the invaluable input of members from the SDWG and NDCAN groups. They've been involved since its inception to ensure the platform is dementia friendly, accessible for everyone, and features products that are tailored to the needs of both those living with dementia and their carers.

The online platform has recently gone through some updates, and once again the group members were on hand to assist in this process with Margaret from SDWG and Maureen from NDCAN only too pleased to narrate the introductory welcome message users receive when accessing the site.

You can follow the link below to listen to the new welcome message, and explore ADAM to discover how it can help you navigate the world of technology with ease and confidence –

<https://www.meetadam.org/>

**Meet ADAM  
(About Digital And Me)**  
Helping you find  
technology products  
matched to your needs.  
Learn more [www.meetadam.co.uk](http://www.meetadam.co.uk)

Alzheimer Scotland  
Action on Dementia

## Connecting carers to support: National AHP Dementia webinar

This engaging webinar, hosted by the national Allied Health Professionals (AHPs), attracted over 120 participants. The key speakers were two of our very own NDCAN members, Ian and Frank, who welcomed the opportunity to share their experiences as carers. They discussed not only the challenges they faced as carers but also the support they received from Allied Health Professionals throughout their journey.



Ian & Frank

Ian and Frank's insights provided a unique perspective on what works well for carers as they shared some personal examples of good practice from health and social care professionals including AHPs.

The feedback from the webinar attendees was overwhelmingly positive. Participants expressed sincere gratitude for Ian and Frank's contributions with many saying their insights have given them inspiration to enhance their own working practices.

If you missed the webinar or wish to revisit the discussions, the full recording is now available at: <https://youtu.be/rsixPfeCnts>

“Thank you for your time and presentation during yesterday's AHP Dementia Webinar. The session generated lots of interest and was well received – and hopefully will support changes and improvements to practice across all settings.”

– Webinar organiser

## Visit to the ASCPP at the University West of Scotland

### Celebrating Professional Debbie Tolson's Retirement

NDCAN members Joanna and Marion, together with SDWG members Margaret, Kenny, and Tony, were delighted to visit the Alzheimer Scotland Centre for Policy and Practice (ASCPP) at the University of West Scotland (UWS).

The occasion was a heartfelt celebration of the retirement of our esteemed friend, colleague, and mentor, Professor Debbie Tolson who has made a significant impact as the Alzheimer Scotland Professor of Dementia; and Director of the ASCPP.





Professor Tolson joined the UWS as the inaugural Director of the ASCPP in January 2013. She is a nurse leader with an international reputation for advancing evidence-informed dementia care and gerontological practice. In 2016, she achieved Principal Fellow Status with HEA UK and was a proud CATE 2020 (Collaborative Award for Teaching Excellence) winner, alongside UWS colleagues and students, for the state-of-the-art 'Class in a Bag: Understanding Dementia' educational resource.

We wish Debbie all the best in her retirement and look forward to connecting in the future where her professional advice will be invaluable as always; and continue to support the work of both SDWG & NDCAN Active Voice groups.



Active Voice members  
& Professor Debbie Tolson

### Members tour the DOMAS Centre

During the visit to the University, our SDWG and NDCAN members also had the opportunity to tour the DOMUS Centre. This award-winning centre is a uniquely designed space that provides valuable insights for students and researchers into how different settings can significantly affect the well-being of people with dementia. The DOMAS centre includes a simulated 'home' environment, along with care and hospital areas, as well as reminiscence and sensory rooms, all tailored to promote learning and awareness.

While exploring this innovative facility, the group members engaged with various adaptations within the rooms, gaining valuable insights into how the home environment can impact on people living with dementia.



## 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 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: [activevoice@alzscot.org](mailto: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."