

From National to International

Active Voice takes its campaigning and awareness raising work to Helsinki

Alzheimer Europe Conference 2023

activevoice@alzscot.org



Under the banner of 'New opportunities in dementia care, policy, and research' 1,000 delegates, including 56 people with dementia and 66 dementia carers/supporters, representing 48 countries, got together in Helsinki between the 16th and 18th October for the 33rd Alzheimer Europe conference. Our national Active Voice groups were well represented with three Scottish Dementia Working Group (SDWG) members, Stuart Dougall (supported by wife Lorraine), Margaret McCallion and Margaret Northedge, and three National Dementia Carers Action Network (NDCAN) members, Anne Tierney, Elaine Deehan and Barry Northedge, in attendance, supported by members of the Active Voice team - making sure that the voices of people living with dementia and dementia carers in Scotland were heard loud and clear.



Elaine, Anne, Stuart & Lorraine

European Working Groups

Before the conference got underway the two European Working Groups, for people with dementia and dementia carers, had two days of in-person meetings.

SDWG member Margaret McCallion is vice-chair of the European Working Group of People with Dementia (EWGPWD), whilst NDCAN member Barry Northedge sits on the European Dementia Carers Working Group (EDCWG). Margaret and Barry participated in interesting and informative discussions on a range of matters relevant to people with dementia and dementia carers across Europe, including legal capacity and supported decision making; anti-amyloid treatments; and inclusive meetings and travel for people with dementia.

People living with dementia at the heart of the conference

Margaret went on to formally welcome people with dementia, their guests, and supporters to the conference at a European Working Group reception to set the scene for the discussions and presentations to follow.

This led into the formal conference Opening Ceremony which concluded with Petri Lampinen, the Finish representative on the European Working Group for People with Dementia, welcoming in Finish all delegates to the event. In a moving and memorable conference highlight Petri's words were translated into English by Chris Roberts, EWGPWD Chair – a demonstration of two people living with dementia in different parts of Europe working together to help improve the lives of people living with dementia.

It was fitting that following the welcome provided by the European Working Group of People with Dementia, the first plenary session of the event was hosted by the group with its members showcasing the work they do around public involvement in dementia research and advocacy.

This was a first for the EWGPWD and, drawing on their own personal experiences, the members from Ireland, Denmark, Czech Republic, and Wales, spoke about their dementia journeys, their work in their own country and internationally, and their public involvement work with researchers across many different projects, sharing their vital insights, as experts by experience.

The session closed with Working Group member Nigel Hullah from Wales asking delegates "Will you stand with us against dementia?" To which he received a resounding "Yes!".

From these initial conference sessions, it was clear that the voices of people living with dementia would be at the heart of the event over the next few days



EWGPWD Plenary Session



Margaret

Ensuring meaningful engagement with those with lived experience

The first day of conference provided an opportunity for our Active Voice delegates to tell their proud story about the way in which they engaged with people with personal experience of dementia to ensure their voice was heard in the consultation on the Scottish Government's 4th National Dementia Strategy.

NDCAN members Elaine Deehan, Barry Northedge and Anne Tierney, provided a powerful and passionate presentation telling how our Active Voice groups engaged with 127 people with dementia and 171 dementia carers who participated in 30 facilitated public engagement sessions. Delegates heard how 'conversation starters' were used to encourage people to speak about their experiences; how dementia had impacted their lives; what worked for them; and what needed to improve.

The presentation outlined what we heard from people, what we learned, and how we ensured this information was front and centre of Alzheimer Scotland's response to the Scottish Government consultation, with 35 recommendations for the future of dementia care and support.

The presentation ended by emphasising that our Active Voice work to deliver better dementia supports and services continues, and an important reminder of the need for action not just strategy.



Elaine



Anne



Barry

The voices of people living with dementia



A session entitled 'Living With Dementia' allowed us to ensure that the voices of people living with dementia were once more at the heart of our conference contribution when SDWG member Margaret McCallion treated delegates to a world premiere book reading.

'Occupational Therapy & Dementia' is an academic textbook which promotes inclusion, rights and opportunities for people living with dementia. The opening chapter of this book was written by members of the SDWG, including Margaret. The presentation at conference provided an opportunity for Margaret to share her writing, highlighting the value of maintaining creative activities, in her case singing, to continue to live a positive life for longer when living with dementia.

Margaret was joined by two of the book's authors, Fiona Maclean and Elaine Hunter, who spoke about the purpose of the book to inspire occupational therapists to be leaders, innovators, researchers and rights-based practitioners in dementia.

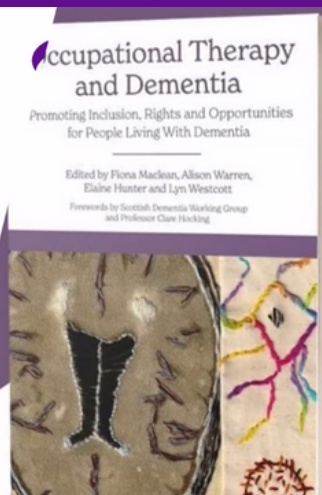
Delegates heard about the importance of having the voice of lived experience at the start of the book, and of the role SDWG members had played in it – from Lorna Noble donating her brain (embroidery) with a note reading 'my brain, please handle with care', to the late Henry Rankin who sadly passed away before publication.

The book closes with Margaret's words so it was appropriate that she closed her contribution with the same incredibly important words that everyone should embrace "no matter what the diagnosis is, always make sure you see the person as a person".

I think when you're doing something with dementia, if you didn't know what it is You should try and find out (**Henry**)

I think the important thing is that I'm still me, even though I have Alzheimer's (**Lorna**)

No matter what the diagnosis is, always make sure you see the person as a person (**Margaret**)



Some quotes from the book

Sharing our rehabilitation lived experience with others

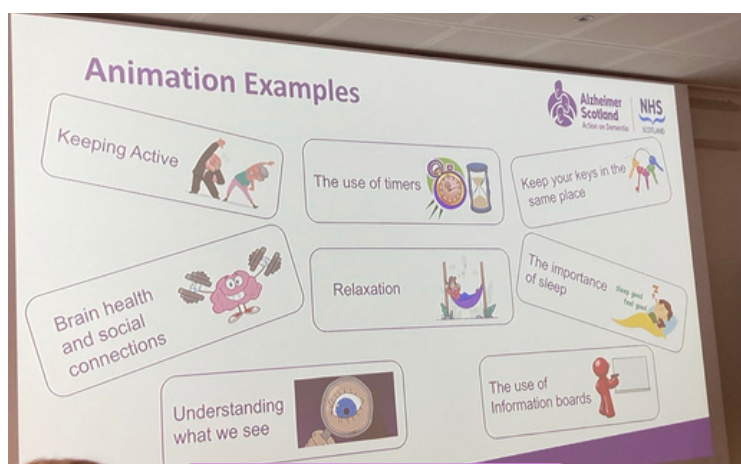
SDWG and NDCAN members are part of a working group including allied health professionals and students exploring animation as a digital solution for sharing rehabilitation advice with people living with dementia and their supporters.

Conference delegates heard from SDWG member Stuart Dougall about this work and how people speaking from lived experience have a powerful message to share with others. As well as speaking about the different animations that have been tested with the voice of experience as narrators, Stuart shared his own story which has been made into a short animation built around the key points that have worked for him.



Some of Stuart's top tips

- have a focus
- have a routine
- keep motivating yourself
- keep trying things you are struggling with
- live your life



Animation examples

The top tips shared by Stuart were very well received in the hall with delegates interested in how these can be shared more widely to benefit people living with dementia. Stuart's story can be viewed [here](#)

Capturing the everyday conversations of those with lived experience

Every day, Alzheimer Scotland's frontline staff hear from people they support locally about what's on their mind; what's important to them; what's working well and what's problematic in their lives.

Supported by the Active Voice team, SDWG and NDCAN members created a toolkit to help capture these everyday conversations and they had the opportunity to showcase this to conference delegates through a poster presentation.

The poster received a huge amount of interest from delegates interested in finding out more about the resources contained within the toolkit and discussing the importance of capturing the recurring issues and emerging themes from these everyday conversations to inform our Active Voice campaigning priorities. Anne, Elaine and Stuart were on hand throughout the day to chat with delegates about the toolkit and about the campaigning and awareness raising work of both the SDWG and NDCAN.



Active Voice members chatting with delegates



Meeting old friends and making new connections

Beyond the organised conference sessions our Active Voice group members took every opportunity to chat with fellow delegates. As well as renewing acquaintances with colleagues we have worked with previously or met at past events, many new connections were made, ideas shared, and potential future projects discussed.

Margaret McCallion and Barry Northedge flew the flag for Scotland during a shift on the Alzheimer Europe information stand, not only representing their respective European Working Groups but also sharing information about the work of the SDWG and NDCAN.

In addition to our Active Voice representatives there was a significant Scottish presence at the conference with delegates including Alzheimer Scotland Deputy Chief Executive Jim Pearson, Alzheimer Scotland Director and Alzheimer Europe Board Member Mary-Frances Morris, AHP and Brain Health Scotland colleagues, partners from the Alzheimer Scotland Centre for Policy and Practice at UWS and friends from several other dementia-related Scottish organisations.

It was clear from our conversations with delegates that Scotland is held in high regard in relation to dementia policy and practice and that the contribution of Alzheimer Scotland, SDWG and NDCAN to the work of Alzheimer Europe and their two Working Groups is greatly valued.

With the 34th Alzheimer Europe conference being held in Geneva, Switzerland in October 2024 delegates were sent on their way with some traditional Swiss Horn music. SDWG member Margaret Northedge couldn't resist having a go and loudly and clearly blew the horn for the fantastic contributions made by our SDWG and NDCAN members over the course of the conference!



Margaret Northedge



Barry & Margaret



activevoice@alzscot.org