

Scottish Dementia Research Consortium (SDRC) Conference - 13 & 14 June 2024

Research is a process of collaboration, and people with lived and personal experience of dementia have a key role to play. This is why members of our two national campaigning groups, the Scottish Dementia Working Group and the National Dementia Carers Action Network are proud to work collaboratively with various research partners, and naturally they were delighted to accept an invitation to the Scottish Dementia Research Consortium's (SDRC) recent conference in Dundee. This annual event had a theme of 'Celebrating Scottish Research and Collaboration' and was jointly organised between the SDRC, NRS Neuro-progressive and Dementia Network, and the Brain Health ARC. The two-day programme featured presentations from key speakers representing different research institutions, disciplines and disease types across Scottish brain health and dementia research.



Active Voice Information Stand

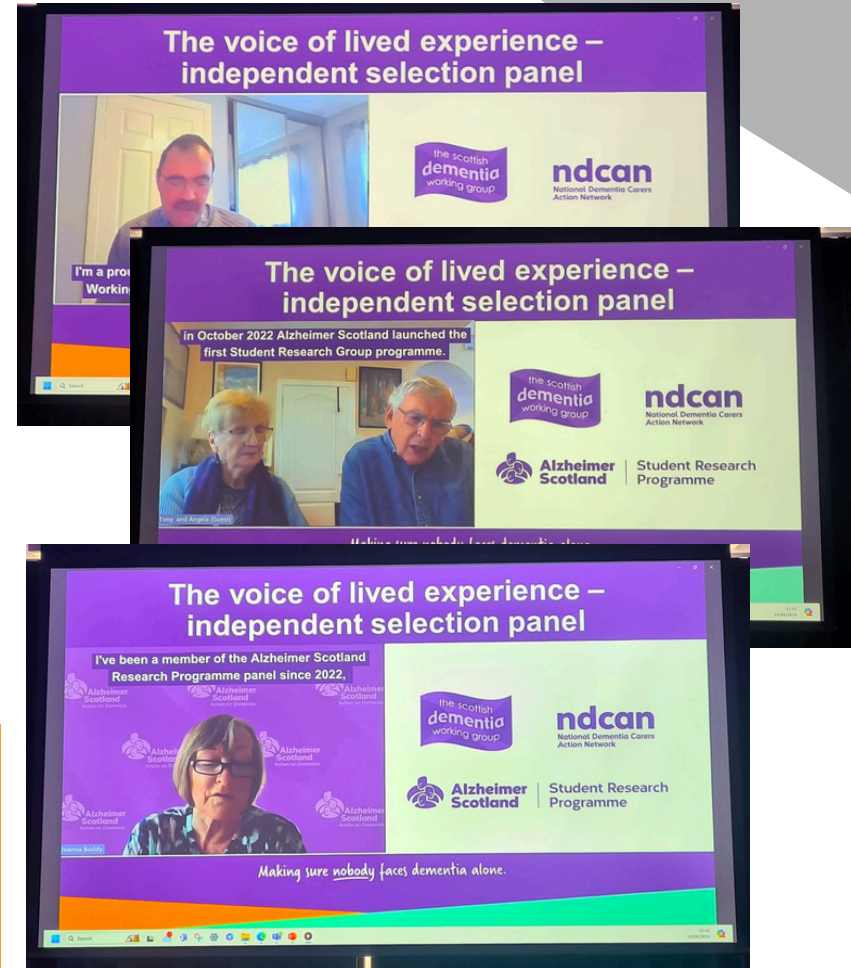
Throughout the duration of the event the Active Voice team were thrilled to facilitate their very own information stand. This proved to be a very popular resource for the conference delegates who were interested to learn more about the campaigning work of NDCAN and SDWG. Moreover, the information stand served not only to enhance the profile of our Active Voice work, but also encouraged positive networking opportunities between our group members and delegates including those with personal dementia experience, and professionals in the field of research.

Alzheimer Scotland Student Research Programme

A highlight of the first day's proceedings was a feature on Alzheimer Scotland's Student Research Programme. The purpose of this programme is to support the next generation of dementia and brain health research by funding studentships at institutions across Scotland. Every year, the successful project is chosen from a very competitive selection process led by members of SDWG and NDCAN. Joanna and Elaine from NDCAN, and SDWG members Kenny and Tony have been involved in the programme since its inception in 2022 and this part of the conference featured a video of the group members expressing the importance of the programme and how they value their involvement. This was followed by an insightful presentation on this year's successful project titled 'Trauma and Dementia Diagnosis'.

"To be involved in research and to be considered a co-researcher has been inspirational because it means you are part of the process and not just the subject of the process." - Kenny SDWG

"Being part of the Student Research Programme is not a token involvement, but the hard work of selection. And that means the research projects relate to the things that matter to the people living with dementia and their carers." - Joanna NDCAN



Experts with Lived Experience

The focal point on day 2 of the conference was the afternoon session titled 'Experts with Lived Experience' and as you would expect, this section featured presentations from NDCAN and SDWG members. On the stage were Frank, Marion and Elaine from NDCAN, and Margaret, Stuart and Rynagh from SDWG who all shared their lived experiences and highlighted how everyone's unique story is invaluable in driving research, awareness, and ultimately support for those impacted by dementia.

"I joined 'Join Dementia Research' shortly after my diagnosis. So far, I've been involved in over a dozen studies. I'm always given details about the study, the what, where, when and how questions plus a choice to opt in or out.... I'll never be a general in this battle - I'll leave that to the experts, but I am a willing recruit." - Rynagh SDWG

"We share out stories and our experiences and enjoy participating in projects which are close to our hearts. I hope you will share your research all over the world. Dementia Research needs you, as does your generation and future generations." - Marion NDCAN



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 and practice – Your Voice Matters! You don't have to be politically minded or need any qualifications to be 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 Voice Team, please email: activevoice@alzscot.org.



Active Voice group members at the conference