

Active Voice

At the Alzheimer Scotland
Annual Conference



20 September
2024

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Welcome to our latest newsletter! We're excited to take this opportunity to spotlight one of the flagship events on the Active Voice calendar, Alzheimer Scotland's Annual Conference, which took place on Friday 20 September. This year's event drew an impressive turnout of over 400 delegates, showcasing the strong commitment to improving dementia prevention, care and cure.

As always, the conference featured prominent contributions from our two national campaigning groups - the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN). Throughout the day, members from both groups took to the stage delivering impactful speeches that positively resonated with the delegates. In this newsletter we reflect on this prestigious event and celebrate the voices of lived and personal experience that are helping to shape the future of dementia in Scotland.

Welcome & Opening Session - Tommy & Maureen

At Alzheimer Scotland, the voices of those with lived experience is front and centre of everything we do, so it was only fitting that Tommy McLean from SDWG and Maureen Huggins from NDCAN opened the conference. Their personal experiences and insights set the perfect tone right from the start.

Tommy, who lives with frontotemporal dementia, shared his journey, reminding everyone that dementia is so much more than just memory loss. He spoke about one of the day's key themes: 'personhood' and emphasised how important it is to see the person first, rather than defining the person by their diagnosis.



Tommy also inspired the delegates by sharing how his diagnosis has led him to explore new interests that help him to live well with dementia. These interests include attending a weekly group at the Clydebank Dementia Resource Centre to joining the 'Every Voice Choir'. Moreover, by becoming an active member of the SDWG, Tommy highlighted how empowering it is to be part of a group that's dedicated to advocating for change and raising awareness.



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

Tommy



Maureen emphasised the importance of incorporating the experiences of dementia carers into policy and practice. After her mother, who had mixed dementia, passed away, Maureen joined NDCAN to highlight the diverse experiences of those living with dementia and their carers. Acknowledging the consuming nature of caring, she referenced NDCAN's new 'For Carers by Carers' leaflets that provide essential advice on self-care, social connections, and maintaining identity. She shared personal stories about her father's dedication to her mother and stressed the importance of support from friends, family, and professionals in building resilience among carers. Maureen concluded by urging attendees to recognise the dual experience of 'living with dementia', affecting both the people living with dementia and their carers.



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There's a phrase that 'if you've met one person with dementia then you've met one person with dementia' and what I've realised is that the same is true of carers

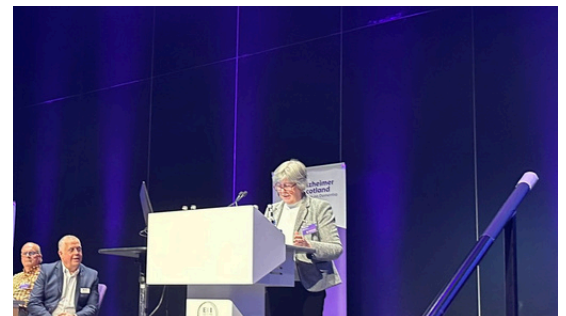
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Maureen

Session 2: Practice Evolutions & Innovations - Rynagh

This session reflected on the 10-year anniversary of the Scottish Government's commitment to post-diagnostic support and provided an update on the world's first Brain Health Clinic, launched just a year ago.

Rynagh from SDWG kicked off the session with her insightful presentation titled, 'Why Practice Innovations Are So Important' where she emphasised not only the definition of innovation as the introduction of new ideas but, more importantly, its impactful outcomes. She added that innovation sparks enthusiasm, broadens perspectives, and fosters continuous adaptation in society. Rynagh then expressed how the classification of the disease as a brain condition rather than a mental health issue, has transformed perceptions and support services. By illustrating personal experiences, she highlighted that the critical role of her Post Diagnostic Support Link Worker served as a vital mechanism for managing the overwhelming reality of the diagnosis, facilitating a transition phase rather than a dead end.



“

Now I look on the diagnosis as a transition phase rather than a full stop. It doesn't change the end but the post diagnostic support was crucial for moving along with a light heart and positive attitude. That must help carers and support services.

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Rynagh

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Session 4: The future of Long-Term Care - Fiona

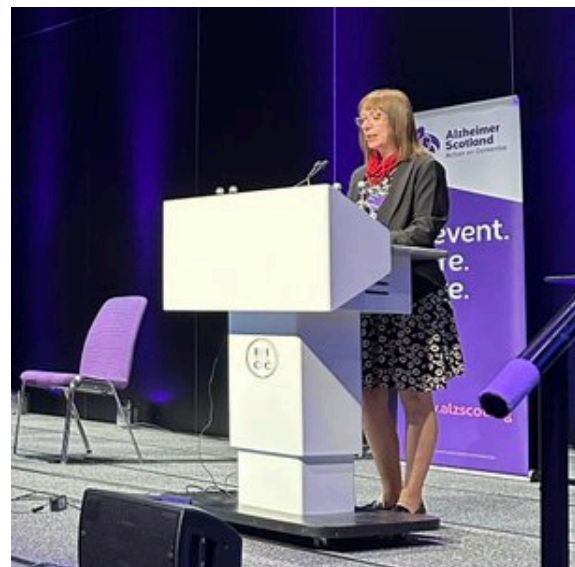
This session focused on the 16 key recommendations from Alzheimer Scotland's report regarding the Future of Long-Term Care in Scotland, which they encourage the Scottish Government to prioritise. It also included insights into the global economic implications and the impact of long-term care for people living with dementia.

In a heartfelt introductory speech, Fiona, a carer for her husband Ian, who has a rare degenerative brain condition which also causes dementia, emphasised the urgent need for reform in Long Term Care Planning. Over the past two and a half years, Fiona has navigated a challenging journey from employing personal assistants to securing NHS Continuing Care, highlighting the inadequacies of current assessment systems that fail to address the unique needs of younger adults with dementia. Fiona advocates for new support models that prioritise individual needs and person-centred care, criticising the existing disparities in care access depending on a person's location and funding status. Fiona believes her personal experience underscores the necessity for collaborative efforts to ensure equitable care for all individuals with dementia, allowing them to retain their identity and quality of life. Fiona concluded with a hopeful note on the potential for rehabilitation when the right support is provided, urging the need for fundamental change to benefit everyone affected by dementia.



There are more ways to look at Long Term Care. Carers have a big voice in this, but we need to plan for it now. It is about getting a model to fit individuals and not making individuals fit into a model.

Fiona

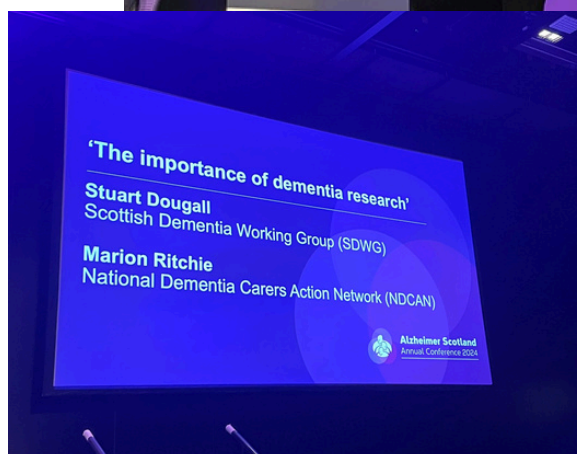


Session 5: Dementia Research in Scotland - Marion and Stuart

Recent headlines have focused on advancements in drug developments and trials for dementia, reflecting a growing momentum in dementia research.

This closing session addressed the current state of dementia research in Scotland and explored future prospects in this field, suggesting that recent breakthroughs may be the start of more significant progress.

Marion from NDCAN and Stuart from SDWG both gave passionate and insightful speeches as part of this session.



Marion emphasised the critical role of research in improving the lives of those living with dementia. Drawing from her personal experience as a carer for her late husband, Marion highlighted the invaluable insights she's gained by participating in various research projects with University of West of Scotland (UWS) over the past five years. She also expressed her admiration for the dedication of researchers, particularly at institutions like the Dementia Research Institute in Edinburgh, where innovative studies on brain health are conducted. Marion stressed the importance of bringing dementia into the media in the hope that it will help to reduce stigma. She called for advocating for advancements in care and prevention strategies, such as Brain Health Scotland's initiatives in schools. Marion concluded by calling for collective action in promoting dementia research, reminding everyone that it holds profound significance for our community and beyond.



I believe that research will change lives for the better. It introduces the public to this word 'dementia' and starts a conversation which is long overdue.



Marion



In contrast to a recent advertising campaign by a national dementia charity, Stuart shared his reflections on the significant moments since his early onset Alzheimer's diagnosis. He emphasised that, despite the challenges he has faced, he has "not died" - and conversely, he remains very much alive and actively engaged in life. He spoke about how his journey has led him to embrace research, providing a crucial perspective on dementia and advocating for the importance of prevention, care, and ultimately, a cure.

Stuart referenced various studies he has participated in, from cognitive testing to innovative studies on healthy ageing, and he highlighted how involving people with personal experiences in research ensures that the studies address real life challenges and issues faced by those living with dementia. Stuart added that being involved in research has not only fostered a sense of purpose but also given him a better understanding of his condition. Stuart's concluding message was to encourage everyone to consider participating in research. He stressed that Scotland's commitment to dementia research is something we can all take pride in and will ultimately benefit future generations



One of the obvious reasons I take part in research is that I can now provide a perspective of someone with dementia, and I feel it would be foolish not share that dimension.

Stuart



Active Voice Information Stand

In addition to our group members presenting at the conference, many more actively participated in facilitating our Active Voice information stand throughout the day. As a team, we were delighted to welcome numerous delegates who stopped by for a chat and expressed a genuine interest in our work. The positive interactions we experienced at our stand were further highlighted by several inquiries from individuals who were keen to learn more about joining SDWG and NDCAN.

This interest not only reflects a growing awareness of our campaigning efforts but also demonstrates the importance of involving those with lived experience in all decisions related to dementia.



Delegates' feedback

Upon reflection, we hope you'll agree that the contributions from SDWG and NDCAN members at this year's conference were poignant, insightful, and powerful. This was further demonstrated by the extensive praise shared by delegates across various social media platforms. The emphasis on the voices of lived experience highlighted the essential role that people living with dementia and their carers play, not just within the realm of Alzheimer Scotland, but across the wider dementia spectrum.



Yvonne Mans... · 20/09/2024 ...

Fiona Catterson

@NDCAN_Scotland taking about long term care 'Need new models of support for younger people living with the dementia' 'long term care should support the person not the person having to fit into long term care'

#AlzScot24



Just a care ho... · 20/09/2024 ...

Stuart from @S_D_W_G getting a resounding applause from the room by reiterating that despite his diagnosis of #dementia, despite the losses he has encountered along the way, despite negative media portrayals, he is very much alive

👏 #AlzScot24



Ashleigh Gray
@ashleigh_gray1

"I may have dementia, but dementia does not define who I am."

Such a powerful start to @alzscot annual conference from Tommy MClean, @S_D_W_G

#AlzScot24

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 Team, please email: activevoice@alzscot.org

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