

From National to International

Active Voice at Alzheimer's Disease International 36th Global Conference

Kraków, Poland 24 - 26 April 2024

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Introduction

Alzheimer Scotland's two campaigning groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) are renowned for their campaigning and awareness raising work on a local and national platform, but did you know they also embrace every opportunity to spread their message on an international stage? If you did, you won't be surprised to read that NDCAN member Joanna Boddy, accompanied by Active Voice Development Officer Norman Williamson, were delighted to look out their passports recently and travel to Kraków in Poland for 'Alzheimer's Disease International' 36th Global Conference.

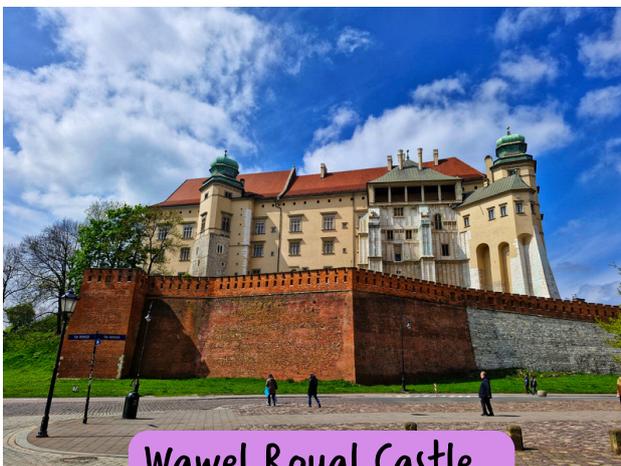
Both SDWG and NDCAN are member led groups, with the SDWG representing people living with dementia, and NDCAN for carers or former carers of a person with dementia



About Kraków

The Monday night flight time meant Joanna and Norman were afforded the opportunity to do a little bit of sightseeing in the afternoon before the conference started. Kraków is the second largest and one of the oldest cities in Poland and as they soon discovered, it is a beautiful and historic place to visit. Their whistlestop tour of the 'old town' began by climbing the hill to explore its grand Wawel Royal Castle and admire the breathtaking views of the city from the grounds. Joanna and Norman then navigated their way through the cobblestone streets eventually finding Kraków's massive market square which is surrounded by impressive buildings that still look just as they did centuries ago.

On the Thursday evening after a long busy day at the conference, Joanna and Norman took advantage of the free delegates travel pass and boarded the tram back into the old town. This of course included another visit to the market square, which as they pleasantly discovered, is even more captivating at dusk when the lights illuminate the colourful buildings.



Wawel Royal Castle



Joanna on the tram

The Conference

Coming together under the theme of 'Dementia: Insights; Innovations; Inspirations; the conference brought together experts from across the world to share information on achievements, innovations and best practices in dementia research, care and policy, while continuing to address and challenge the perceptions around dementia. Flying the flag for Alzheimer Scotland and the members of NDCAN and SDWG, Joanna and Norman were not only honoured to attend this prestigious biennial conference, but moreover to be chosen to give an oral presentation ('Every Story Matters'), and also a poster presentation (Coffee with a Cop).

'Every Story Matters' presentation

In their oral presentation, titled 'Every Story Matters', Joanna and Norman began by explaining that narratives around dementia have historically been negative, and all too often, they have not been shaped by people with lived and personal experience. Conversely, they went on to highlight how members of SDWG and NDCAN are positively changing the narrative by drawing on their personal stories as people affected by dementia; and sharing these stories at meetings, speaking at conferences, participating in webinars, and in some instances by appearing on TV or radio. Joanna and Norman also illustrated during their presentation how both campaigning groups believe that sharing their personal stories enables them to connect better with their audience, helps to get decision makers to listen, and ultimately to makes it more likely to influence and inspire positive change.

To emphasise how powerful the power of storytelling can be, Joanna and Norman alternated between the lectern to read out poignant but inspiring excerpts and quotes from some of the members personal stories. This culminated in Joanna sharing her own intimate story about being a carer to her mum, Vera. Joanna, who has been an NDCAN member for eight years, then articulated how she has told her story in various settings to campaign for change, and to help ensure carers' needs are recognised.

"I was a daughter first and didn't think of myself as a carer for a long time – like many family carers. This can mean our voices are often not seen or heard, or our needs recognised. As part of NDCAN I campaign to make sure they are and that we are valued and seen as equal partners in care" - Joanna



The presentation

Joanna and Norman concluded the presentation with a famous quote from Professor Tom Kitwood who said:

"When you've met one person with dementia, you've met one person with dementia."

They explained that this quote underlined their message that every single story is unique, and members from SDWG and NDCAN recognise there is something to be learned from each individual experience.

'Coffee with a Cop' poster presentation

The Active Voice poster presentation - 'Coffee with a Cop', was displayed throughout the three day conference. The poster illustrated how both SDWG and NDCAN are working to build a positive collaborative relationship with Police Scotland. One such initiative was the 'Coffee with a Cop' event aimed at bringing the group members and others affected by dementia in the community, together with community police officers to discuss relevant issues and learn more about each other. As detailed in the poster, the 'Coffee with a Cop' idea not only allowed the attendees to see the police are approachable, but also gave an opportunity to raise awareness about dementia and discuss various initiatives that are available to help people live safely with dementia.



Joanna networking at the poster

Learning and networking opportunities

It goes without saying that the two presentations were a particular highlight of the conference for both Joanna and Norman. However, with this international event attracting over 1,000 delegates from over 120 countries around the world, they also embraced the three full days of compelling learning and networking opportunities.

Joanna and Norman enjoyed meeting and having conversations with a wide range of delegates. This included a documentary film director from USA who recently made a film which explored personhood within the context of dementia with the native American Paiute Tribe at Pyramid Lake, Nevada. Interesting to note that the tribe don't have a word for dementia in their vocabulary.



Joanna with a representative from the Bahama's Alzheimer Association

Another very engaging conversation was with the friendly delegates representing Bahamas Alzheimer's Association who were in awe of our work in Scotland after explaining that their organisation, the first of its kind in the country, was only founded in 2020.



A hot topic amongst many delegates was the recent controversial campaign by the Alzheimer Society titled 'The Long Goodbye'. Joanna and Norman found it interesting to know that the views and disapproval of both SDWG and NDCAN were shared widely. They also had the opportunity to discuss these with a delegate from Alzheimer Society (who had not been involved in the campaign) who was sympathetic to the concerns although finished by pointing out that "it's got a lot more people talking about dementia".

The plenary sessions were wide-ranging and provided lots of food for thought. Several presentations talked about the needs of young carers and there was a particularly powerful presentation from the wife of a person with younger onset dementia on the need for support for the children of a parent living with younger onset dementia. Another focus was inequalities in dementia and the need for services to be culturally sensitive as well as accessible to different groups. This topic identified some points for us to think about in Scotland. Other points of discussion included inputs on palliative care and timely versus early diagnosis.

And finally...

A take home message shared by both Joanna and Norman was to appreciate how much Alzheimer Scotland (steered by the voice of lived experience) has led in the field of dementia, prevention, care and research and how this has influenced dementia policy both in Scotland and other parts of the world. However, lots of work remains to be done in Scotland and whilst we are ahead in many areas, attending the ADI Conference has, for Joanna and Norman, reaffirmed that there is still opportunity to learn from the experiences in other countries.

We look forward to sharing more of our innovative practice at the next ADI Conference in France 2026.



Joanna & Norman presenting



Selfie in Kraków old town