

# Active Voice

at the 34th Alzheimer Europe  
Conference, Geneva  
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Members' experiences



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## Introduction

Our annual opportunity to be part of the Alzheimer Europe conference did not disappoint this year. The conference was held at the Geneva International Conference Centre which is located in the centre of the beautiful Swiss city. There were impressive transport links by both land and sea, beautiful architecture and lovely warm and friendly people who spoke English well, whilst also not laughing with our attempts to speak French.

This report shares with you the experiences of some of the attendees, SDWG and NDCAN Members, Rynagh Flynn, Maureen Huggins and Thea Laurie who have all written their own individual reports. They not only attended the conference, but presented too, sharing the work of Active Voice, and their personal experiences under the themes of Dementia Work Force, Public Involvement in Research, and Young Onset Dementia.



Margaret presenting

Day one gave the opportunity for Active Voice members and Alzheimer Scotland representatives to support European Working Group for People with Dementia (EWGPWD) member and the current SDWG representative, Margaret McCallion as she took to the stage at the parallel session titled- 'People living with dementia'. Margaret shared the stage with fellow members of the group who all spoke about their different individual experiences of living with dementia.

The room was packed, and you could hear a pin drop as each member of the EWGPWD stood up at the lectern and told their stories. SDWG Member Margaret shared her experiences and talked about how she has come to terms with her diagnosis and is "living her best life". Margaret inspired people in the audience and received positive feedback and questions. One member even declared his love to Margaret and thanked her for her honesty and positivity.

In her role as a member of the European Working Group, Margaret also had Committee and update meetings to attend over the 3 days, working hard and being a fantastic ambassador for Scotland.



Alzheimer Scotland's Head of Comms & Campaigns, Jess Bruce, and Margaret

# Members' Reports

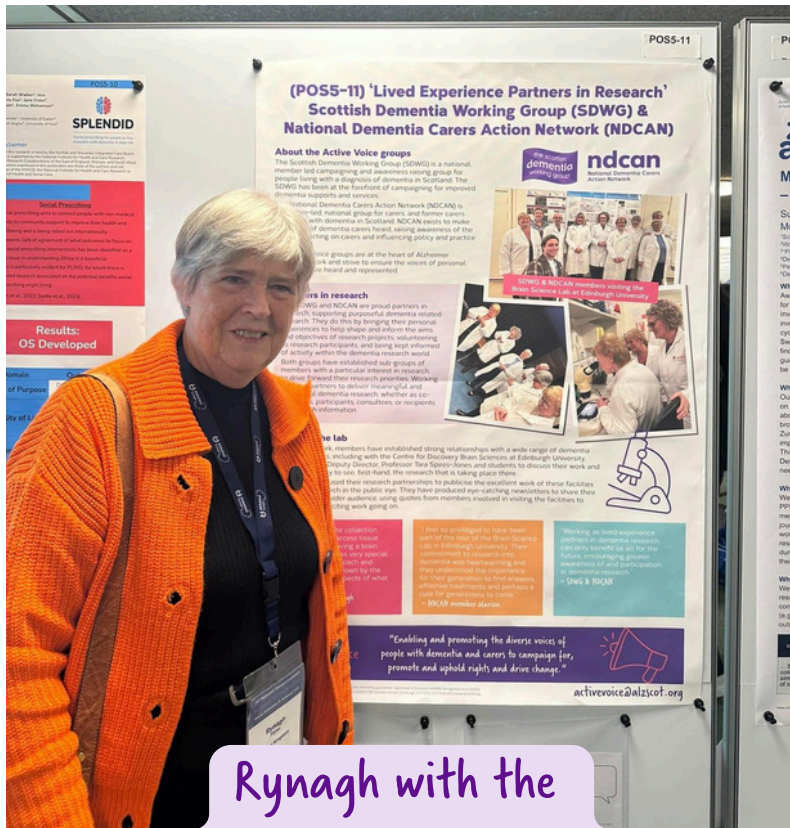
## SDWG Member Rynagh Flynn

Rynagh presented at the conference on day 2 at a session of 10 quick oral presentations. She shared her experiences of being part of the 2023 Alzheimer Scotland winter campaign – Dementia Research - We're All in - where a series of short campaign films were made with three people with a dementia diagnosis including Rynagh and fellow SDWG member Kenny Moffat.

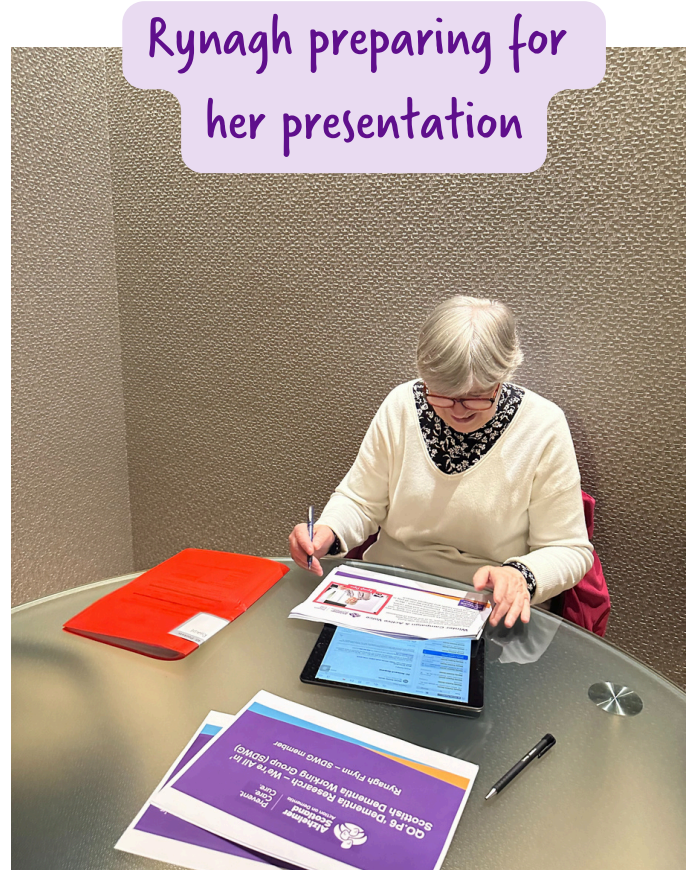
She shared her hopes and aspirations around dementia research, said how important it was to involve people with lived experience and emphasised that it should be a priority. Rynagh was able also to tell people about the reach of the campaign through statistics that had been shared with her through the close work with the Alzheimer Scotland Communications and Campaigns team. She told the audience that to reach over 150,000 people in the course of a month was impressive.

“Research is one way for me to find out progress, find out more about what’s being done, what’s out there and to meet other people.”

Rynagh’s presentation on research gave her the opportunity to signpost people to our poster ‘Partners in Research’ which came under the Inclusion and Intersectionality theme. It showcased the work of Professor Tara Spires Jones and her team at the Centre of Discovery Brain Sciences at the University of Edinburgh and how they involve people with lived experience in everything they do as researchers.



Rynagh with the poster presentation



Rynagh preparing for her presentation

## Read Rynagh's report of her experience of attending the Conference:

As a first timer at an Alzheimer Europe Conference, I was blown away by the range and scale of all the activities that were happening in so many different rooms and spaces and levels all over the complex. Thankfully, Wendy had us all in hand, shepherded us to where we needed to be and managed everything magnificently with a good spirit and a smile.

The organisation at the venue was fine-tuned and included a dedicated room on the ground floor for those of us with dementia where we could regroup, relax, eat our lunch, and meet other people from different countries who are sharing the dementia journey and chat with them.

One thing of note was how progressive Scotland is in comparison to other countries. An example of this is the allocation of a Community Link Worker for post-diagnostic support in Scotland. This is a goal that hasn't been realised in so many countries and speaking personally, the benefits it has brought has been essential in terms of acceptance, planning and moving on. There were several conversations with delegates from other countries who are in process of making this a reality in their homeland, and others wanting to know more.

The seminars were timed to the minute with speakers given 5 minutes for their presentation, including videos and graphics. Then you were shown a red card. That too can be an achievement and a relief!

Overall, the conference was engaging, informative and a treasured memory.

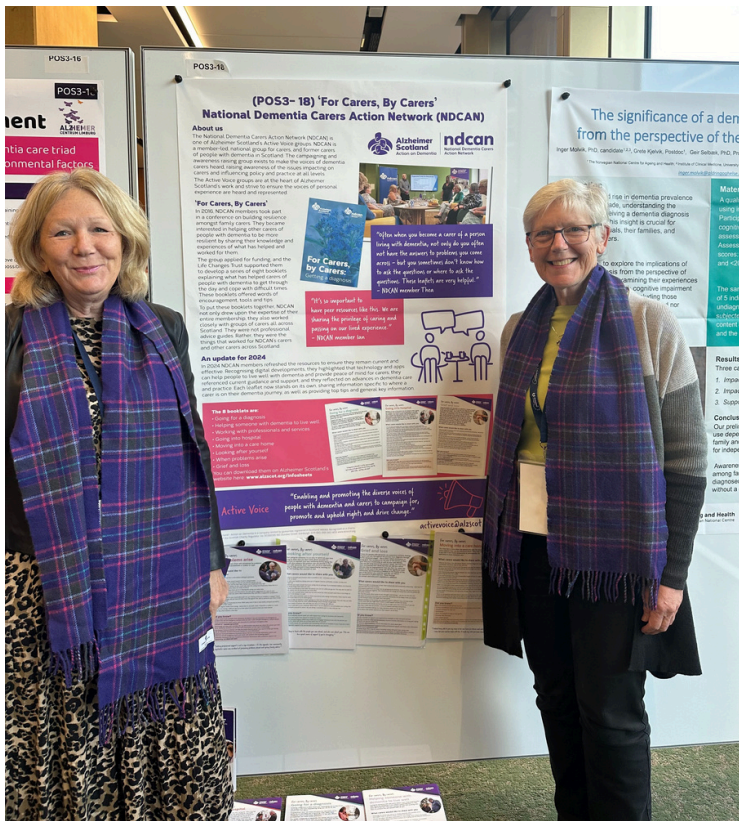
Rynagh Flynn

## NDCAN Members Thea Laurie & Maureen Huggins

NDCAN Members Thea Laurie and Maureen Huggins gave a very different and unique presentation at their parallel session on day 3, sharing their experiences on how Active Voice supports workforce development.

Thea and Maureen had a 'conversation' and interviewed each other as they spoke about what NDCAN do and the work they have been involved in. This included, hospital improvement programmes, speaking to speech and language students and most recently with NHS Education for Scotland (NES) for a training film for health and social care staff. A key question to each other was *Why do you do this? Why are you part of NDCAN?* – they both spoke passionately about good and bad experiences they experienced when their loved one was receiving care. An important message from Maureen was to "please involve the family"

Active Voice also had a poster presentation of the NDCAN new leaflets – For Carers By Carers – Poster 3 "Living with Dementia", and this was on display alongside a suite of the revamped leaflets. Both Thea and Maureen were part of the working group reviewing the content, so it was very apt they were both in Geneva to share the leaflets with attendees. Ever the professionals, they finished their presentation by directing people to the poster and waving the leaflets to the audience, get your copies here!



Thea & Maureen at the 'For Carers, By Carers' poster and presenting

## Read Thea's report of her experience of attending the Conference:

Don't hesitate to sign up for a place with the Alzheimer Scotland contingent, if the chance comes your way to attend a future Alzheimer Europe Conference. To describe it as both exhilarating and exhausting, is probably a good start to a report.

Being in Geneva for a European conference in a huge conference centre, right next to the UN building for Refugees, maybe hints at what a magnificent few days await you, but I will confess, I had no idea just how fascinating it was going to be. As soon as you receive the Conference Programme Book, you understand the immensity of the event which is prepared and hosted jointly by Alzheimer Europe, Alzheimer Suisse and Alzheimer Geneva. Whatever your interests in dementia are, there will be sessions devoted to it. By the end of the first day you realise you can't attend everything and need to be realistic about what you can participate in.

By the end of the conference, we were all agreed that the theme 'New Horizons- Innovating for Dementia' had been covered from every angle. There are new horizons, and to learn first-hand about the promising new innovations was inspiring. At the same time, we agreed that Scotland is ahead of much of Europe in many areas thanks to the direction and lead taken by Alzheimer Scotland. It is impossible to recount every session that we attended. Instead, I will list my 'highlights'.

Sessions led by, or including people with lived experience were poignant and powerful. The opening session 'Navigating dementia together', in particular set the tone which was full of hope, and the strong message from both people with dementia and carers - that although things change - you can live well by approaching diagnosis with positivity. One of these sessions ended with a person with dementia singing 'You'll never walk alone' unaccompanied. He received a standing ovation.

Brain health and prevention were key priorities. Research from Italy, Germany, the Netherlands, in fact from across Europe dealt with progress in areas as varied as causes for cognitive brain damage to data on studies on ageing and predicted sharp increases in numbers of people with dementia in lower and middle-income countries.

A session I particularly enjoyed was on arts and dementia where speakers focused on the power of art, dance, drama and especially music which can improve emotional wellbeing, social isolation, enrichment and empathy. Non-pharmaceutical routes have real value. There was a plethora of sessions on treatments and especially on innovations in new Alzheimer's disease drugs. A session on biomarkers by a Swiss professor, spelled out how dramatically they will improve diagnosis in the very near future. Debates about the difficult financial decisions highlighted that the position is not as bleak as it may appear.

Overall, the message from the conference, is that new innovations in drugs are a hugely positive step forward and the delay in using the drugs is not necessarily related to the cost of the drugs but to lack of facilities to administer and monitor within healthcare systems. The next generation of drugs may not require to be administered intravenously but taken in tablet form at home.

Listening to policy sessions was also an indication of how Scotland (despite how it sometimes appears to us) is leading the way. I enjoyed listening to three members of Alzheimer Scotland staff as they unraveled how, in their roles, they dealt with improving outcomes for people through forward planning, legal support of Power of Attorney and, of course the Long Term Care Commission.

NDCAN and SDWG members also presented at sessions on how our groups support the workforce and how to live your best life with dementia. We also generated interest when our posters were on display. NDCAN and SDWG were also part of the content from our colleagues in the UWS during sessions on young onset dementia with the work co-produced on career guidance. Another session on the success of the Carers Academy referenced the strong links to Alzheimer Scotland. Our links with the research at The Brain Tissue Bank also featured.



If you do attend the European Conferences of the future – be sure to wear your Alzheimer Scotland tartan scarf. It's an immediate ice breaker. I was really surprised by the number of people who clocked and recognised it. Just wish I had taken a suitcase full of them to sell!

I would just like to say a final word of thanks to the team who booked and organised the whole trip, especially Wendy who was on call for us all 24/7.

## Read Maureen's report of her experience of attending the Conference:

It was my first time at an international dementia conference and I found it an extraordinary mix of high science, practical dementia care and true life stories from those with dementia and their supporters. The true life stories were uplifting, the practical dementia care alarming but heartening that people were trying to make improvements, and the high science – well I looked at the posters but didn't go to the sessions because I thought my head might explode.

I hope that the practitioners at the conference were in the sessions where people living with dementia were explaining what their life was like and what things made a difference to them. There were many talks that helped me understand. For example, a lady with Lewy body dementia said her brain was like “a desk where every day someone rearranges the papers”, and that she calls her hallucinations “unexpected guests”. I've noted many insights from the lived experience speakers and hope to use them in dementia awareness training

I went to a couple of sessions about dementia in different ethnic groups, something which I have no experience of but I know that NDCAN is conscious that ethnic minorities are not properly represented among our membership. What I found interesting was that researchers realised that sometimes the issues with reaching ethnic groups are fundamental eg 1st Nation people in Canada not identifying with the label 'dementia', or African and Caribbean communities in the UK thinking that mild dementia was a normal part of ageing and not wanting to talk about what they thought of as mental health issues. But there were also practical barriers such as services not meeting cultural needs like food, and loss of memory making it difficult for Muslims to attend prayer leading to isolation from their community. Everyone was saying that there was a need to sensitively explore the barriers, overcome stigma and coproduce solutions. But also, as new generations come up these barriers might change.



Maureen with Owen Miller  
from Alzheimer Europe

As for the practical dementia care, I hope you don't mind me finishing on a negative note. Two talks, both about practice in England, remain prominent in my recollection, the only positives being that the speakers were honest about their findings and keen for change. The first was about link workers attempting to social prescribe for people with dementia without having the proper training. Most of their visits weren't face to face and there was a lack of imagination in what activities they were suggesting. There was not much benefit for the person with dementia but more so for their supporter, probably because the link workers felt more 'comfortable' talking to the carer. The second was given by a doctor that took it upon himself to observe restrictive practice on hospital wards, talking to staff, patients and visitors. He found that people didn't always understand what is classed as restraint, so 1 to 1 observation where the patient was stopped from moving out of a chair, sometimes by a security guard, was not always thought of as restraint. Can you imagine how frightening that must be? Often people with dementia were restrained in anticipation of them needing it. He called for anyone interested in doing research on how to change things to come and see him – I almost signed up!

As Thea has said, it was an experience and I would recommend it to anyone else that has the opportunity. I have an exercise book full of notes and ideas and I hope I will be able to put them to good use.

Maureen & Thea



## Collaboration

A big part of what we do at Active Voice is collaboration – and we do this well with our colleagues at the Alzheimer Scotland Centre for Policy and Practice, University West of Scotland.

The conference gave the opportunity for a project that members have been involved in over the past 2 years to be presented. Margaret McCallion and Rynagh Flynn took to the stage alongside Dr Laura Lebec and Professor Louise Ritchie as they all spoke about the project 'Guidance of Life, Work and Career – Dementia in the Workplace – Career Guidance'. Margaret and Rynagh spoke about their involvement in this project as co-researchers, and share a film that they were part of giving an overview of the process and approaches used.



## To sum up...

As the conference closed it was exciting to have the announcement for the next Alzheimer Europe Conference which will be held in Bologna, Italy under the banner 'Connecting science and communities: The future of dementia care'.

Scotland is held in high regard in Europe and as world leading in policies and practices that we have. Alzheimer Scotland had colleagues who presented on Post Diagnostic Support and the Long-Term Care Commission, many people in the audience were in awe that here in Scotland we are leading the way, and that people with lived experience are our key drivers

