

Active Voice

Dementia Awareness Week 2023 Newsletter

activevoice@alzscot.org



Coffee with a Cop

Dementia Awareness Week 2023 got off to a flying start on Monday 29 May for our national Active Voice groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN), when they got together in Alzheimer Scotland's Brain Health and Dementia Resource Centre in Glasgow for a 'Coffee with a Cop' Tea & Blether. Members were joined by officers from Police Scotland to chat about the range of initiatives that are available to help people live well and safely with dementia.



There were great conversations about tools such as the Herbert Protocol, Purple Alert, and the Dementia Safeguarding Tag, as well as discussions about apps and devices that can play a part in helping people with dementia, their carers and families to live securely and have peace of mind.

Members shared their personal experiences and gained valuable information from the police representatives.

Visit to Stirling Central Library

The following day SDWG and NDCAN members took their campaigning and awareness raising message to Stirling and the Borders. Christine & Bill Alexander (SDWG & NDCAN members respectively) were at the Stirling Central Library for the launch of a new Alzheimer Scotland partnership to establish dedicated Dementia Information Hubs in over 120 community libraries across Scotland. The partnership seeks to build on the many years of working with local libraries in our localities and will help us reach more people living with dementia across Scotland. Christine & Bill spoke about their own personal experience and of the importance of being able to access dementia information, services, and activities locally.

The launch was well covered by the media, such as the Herald which carried a lovely article with great photos of Christine and Bill.



Borders Dementia Working Group

At the Borders Dementia Working Group in Galashiels Maureen Huggins, promoted the work that NDCAN does to champion change and tackle stigma. Maureen also took her message to Lanarkshire later in the week when she attended the Young Onset Dementia Café at Alzheimer Scotland's Dementia Resource Centre in Motherwell.



National Dementia Learning & Sharing Network

Our work to enable and promote the voices of people with dementia and carers continued on Wednesday 31 May when NDCAN member Marion Ritchie and SDWG member Kenny Moffat participated in the National Dementia Learning & Sharing Network, attended by over 100 health and social care professionals including Dementia Champions, Dementia Specialist Improvement Leads and Dementia Ambassadors. Kenny and Marion spoke about their personal experiences of living with dementia and caring for a person with dementia. They also highlighted some of the work they are involved in through their respective Active Voice groups.

SDWG Priorities & Focus Areas 2023/24

Dementia Awareness Week was the ideal time for the Scottish Dementia Working Group to launch their new Priorities & Focus Areas for 2023/24, and members were delighted to be able to do this on Wednesday 31 May. The new campaigning & awareness raising commitments were informed by the personal experiences of people living with dementia and cover six key priorities – Dementia supports & services; Brain health; Influencing policy & practice; Research; Equality & Diversity; and Tackling stigma. The specific commitments include areas of focus around pre and post diagnostic support; young onset dementia; an improved diagnosis pathway; and support for people with Mild Cognitive Impairment (MCI). The forthcoming work of the Group will align with their new priorities.



Junior Doctors Learning Session

The SDWG's commitment to ensuring workforce knowledge and practice are informed by people with personal experience was at the heart of a learning session with year 1 junior doctors from Wishaw General Hospital on Thursday 1 June. Group members Margaret McCallion, Stuart Dougall and Kenny Moffat spoke about their diagnosis journey, their experience of receiving a dementia diagnosis in their 50s, their life since and how they are living the best life possible with dementia, including through their work with the SDWG. They took the opportunity to highlight the key things the junior doctors should keep in mind when giving a dementia diagnosis.

Research Themed Tea & Blether

This was followed by a research themed Tea & Blether at which SDWG members got together with Professor Debbie Tolson and Dr Louise Ritchie from the Alzheimer Scotland Centre for Policy & Practice. The Group has enjoyed working closely with the Centre since its inception 10 years ago, so it was great for members to meet with Debbie and Louise in the Glasgow Brain Health & Dementia Resource Centre to review the work they've done together and look forward to future research opportunities.

Members chatted about the ways in which they can participate in research – from receiving information on research projects; to being consulted on and participating in research; and to working with the Centre on a co-production basis. Conversations took place about possible areas for future research, and around how the Group can identify and develop project ideas that align with their renewed priorities and focus areas. Members agreed to establish a research group to build upon their research partnerships with the Centre for Policy & Practice, Brain Health Scotland and the Scottish Dementia Research Consortium.



Meeting with Professor Tara Spires-Jones

The research theme continued on Friday when SDWG and NDCAN members got together with Tara Spires-Jones for some fascinating insights from the Alzheimer Scotland Brain Tissue Bank. Tara, an Alzheimer Scotland Ambassador, a neuroscientist and the Deputy Director of the Centre for Discovery Brain Sciences at the University of Edinburgh, provided an overview of Alzheimer's disease pathology and discussed how brain tissue donations are advancing knowledge.

Group members heard about how brain tissue samples have taught us important lessons about brain ageing, why some people are resilient to cognitive decline, and how pathology spreads through the brain in Alzheimer disease. The session provided an opportunity for members to chat with Tara about some of the recent dementia drug discoveries and the ongoing scientific research. They also had the opportunity to look at brain tissue samples showing the build up of tau protein, which can lead to dementia.



NDCAN Business Meeting

The week drew to a close with NDCAN members coming together on Saturday 3rd June for a business meeting, to review their work over the last year and to consider their forthcoming campaigning and awareness raising activities. Members had great discussions covering a wide range of issues experienced by dementia carers and they considered their priorities and focus areas for 2023/24 which will be published shortly.



A wonderful week...

Members of both the Scottish Dementia Working Group and the National Dementia Carers Action Network also supported and helped to shape the content of Alzheimer Scotland's week-long Dementia Awareness Week campaign– particularly 'Talking our language' which aims to challenge the stigma and preconceptions people with dementia often face.

SDWG member Stuart Dougall played a key role in Alzheimer Scotland's national DAW communications, as one of 5 people who shared their experience of young onset dementia through a short film and a blog. Stuart also appeared on the cover of the Dementia Awareness Week edition of Dementia in Scotland Magazine, and wrote about why dementia didn't stop his recent South American adventure. SDWG member Margaret McCallion also appeared in the magazine, sharing what she'd like people to know about life with a diagnosis of young onset dementia.

Throughout our week of activities SDWG and NDCAN members promoted Alzheimer Scotland's key Dementia Awareness Week message that dementia is 'One thing, not everything' about a person. They demonstrated that a person can continue to live well following a dementia diagnosis, and they played their part in tackling the stigma of dementia.



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