

# Active Voice

## Dementia Awareness Week 2024 Newsletter

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# Reflecting on Dementia Awareness Week 2024 (27 May – 2 June)

## SDWG & NDCAN

It would be fair to say every week is Dementia Awareness Week for our two national campaigning groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN). This is because the group members work tirelessly all year round to influence policy, challenge stigma and raise awareness of the disease. Nevertheless, Dementia Awareness Week is always a highlight of the groups' calendars, and this year was no different with the group members embracing the opportunity to participate in no fewer than nine events. In this Dementia Awareness Week specific newsletter, we feature some of the highlights of what turned out to be a very busy week for both our campaigning groups.



Kenny presenting



Bill presenting

### Monday 27 May:

### Future of Long-Term Care report launch

The week started with both groups being well represented at the launch of a report which provides recommendations on the Future of Long Term Care in Scotland. This radical report was produced by a 'commission' which was specifically set up in 2022 to review options in relation to long term care. Members of both SDWG and NDCAN have been key members of the commission from its outset and indeed, contributed to the content of the report. In recognition of their involvement, Kenny from SDWG and then Bill from NDCAN gave a presentation at this well attended event and both outlined what long term care means to them, and why the recommendations of this new report are so important.



The report

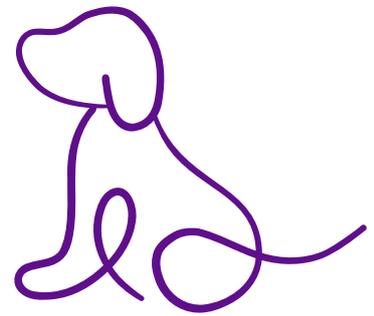
Monday 27 May:

## 'Tea and a Blether' with the Dementia Dogs

SDWG and NDCAN members always welcome the chance to get together to discuss dementia issues and this 'Tea and a Blether' event gave them the perfect opportunity to do just that in a relaxed setting. Following the tea, coffee and cupcakes, the members met with Dementia Dogs Josie and Sandy. Next up was an insightful presentation on the Dementia Dogs project which explained how the trained dogs can provide support to a person living with dementia by prompting daily routines. Following the presentation, everyone looked out their pens and dabbers for a fun game of Doggy Bingo where Josie and Sandy were only too pleased to show off their skills by drawing the numbers.



The Dementia Dogs!



Tuesday 28 May:

## Golden Jubilee Hospital dementia friendly initiative

SDWG member Tony was guest at the Golden Jubilee Hospital in Clydebank for a meeting with their Dementia Lead Nurse, and Design and Equalities Lead, in relation to their plans to make the hospital as Dementia Friendly as possible. Tony has been involved in this initiative for over a year now by giving advice and suggestions on possible improvements from his own perspective as a person living with dementia. This visit included a tour of the patient wards and Tony was encouraged to see that dementia clocks have already been installed in every room.

Another pleasing aspect of the visit was visiting the Dementia Awareness Week information stand which further demonstrates the hospital's commitment to supporting people affected by dementia.



Tony



The information stand

Tuesday 28 May:

## Alzheimer Scotland Centre for Policy and Practice

NDCAN members Joanna and Marion were proud to represent Active Voice at the signing of a new strategic partnership agreement in relation to Alzheimer Scotland Centre for Policy and Practice (ASCPP) at University of the West of Scotland (UWS). By combining their expertise, UWS and Alzheimer Scotland, through the ASCPP, are making a significant difference in the lives of families affected by dementia and improving standards of care. As members of NDCAN, Joanna and Marion have formed strong ties with colleagues at the ASCPP. Indeed, lived experience has been central to the work of the ASCPP since its inception in 2013, and the involvement of SDWG and NDCAN members has been key to the success.



The signing of the new strategic partnership agreement

Wednesday 29 May:

## SDWG and NDCAN meeting with Chief Executive Henry Simmons

The Active Voice of people with dementia and carers is at the heart of Alzheimer Scotland's work. Therefore, it is no surprise that the organisation's Chief Executive Henry Simmons always welcomes the opportunity to meet with SDWG and NDCAN and it seemed fitting to facilitate this particular meeting during Dementia Awareness Week. During these interactive meetings Henry updates us on the organisations campaigning priorities with the group members sharing their views and opinions in relation to each topic. This meeting generated a lot of discussion and covered issues such as long-term care, dementia research and drug trials, and the importance of promoting positive language about dementia



Meeting with Henry

Wednesday 29 May:

## 'Dementia in the Workplace' film launch

A large turnout from both groups enjoyed the official launch and first public showing of the 'Dementia in the Workplace' film. This awareness raising production features SDWG members Kenny, Stuart, Rynagh, and Margaret (with husband Barry) all sharing their stories on being in employment at the time of receiving a dementia diagnosis. The film is part of a long-standing 'Career Guidance and Dementia Research Project' which SDWG members have been involved in over several years with our partners at the Alzheimer Scotland Centre for Policy and Practice (ASCPP)



'Dementia in the Workplace'  
film launch

Thursday 30 May:

## Raising awareness with medical students

Both SDWG and NDCAN campaign to ensure conversations around improving the Health and Social Care workforce are not focused solely on the people providing the care but should always include the people receiving the care. Linking this ideology to Dementia Awareness Week, Stuart from SDWG, and Thea from NDCAN were pleased to take the opportunity to meet with students who are currently studying medicine at the University of Dundee.

Stuart and Thea both shared their personal dementia experiences and outlined some of their campaigning and awareness raising work as a member of their respective groups. Their overarching message to the students when embarking on their chosen careers is to adopt a person-centred approach to dementia by seeing the person beyond the disease; and recognise carers as equal partners in care.



Thea & Stuart



Friday 31 May:

## Active Voice information stand

Our group members are always keen to hear from the quieter voices of people with dementia and their carers. Moreover, they appreciate there is no 'one way' of engagement and will utilise various methods as a way of connecting with people up and down the country. One such approach are dementia specific information days and during this Dementia Awareness Week, Marion from NDCAN and Rynagh from SDWG were only too pleased to accept an offer to host an Active Voice Information Stand at West Lothian College.

The event was organised by West Lothian Post Diagnostic Support team and attended by locals who are currently receiving post diagnostic support (or on the pds waiting list). Marion and Rynagh enjoyed having conversations with a constant stream of attendees, and as well as giving peer-support, they embraced the opportunity to raise awareness on the importance of our Active Voice work, informed on how every voice really does matter, and provided a platform for people to have their say.



Marion & Rynagh

## Sharing their stories

SDWG and NDCAN members believe that telling their story helps to connect better with their audience, gets decision makers to listen, and ultimately makes it more likely to influence and inspire positive change. And so, they never miss an opportunity to share their own personal stories, and by doing so, they hope to change how dementia is understood. During this Dementia Awareness Week, SDWG member Margaret, and NDCAN member Elaine participated in Alzheimer Scotland's national promotion to help raise awareness. Margaret features in a video and talks about what living well means to her. Elaine shares her story in a blog which focuses on her family's experience of having to pay for care.



## Active Voice

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