

## **SDWG & NDCAN at the City of Glasgow College: Incorporating lived experience into Health and Social Care education**

As the new year kicked off, members of the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) wasted no time getting straight back into their vital work of campaigning and raising awareness about dementia.



In this recent collaboration on 8 January, Stuart and Margaret from SDWG, alongside Marion from NDCAN, welcomed the opportunity to connect with Health and Social Care students at City of Glasgow College. As always, their presentations were not only enlightening but were also a poignant reminder of the critical role that lived experience plays in understanding and addressing the complexities of dementia. Indeed, for both SDWG and NDCAN, the participation of individuals with lived experience of dementia is essential in shaping the education of future health and social care professionals.

The session began with a presentation from Norie, Active Voice Development Officer, who emphasised the importance of incorporating the insights of individuals with lived experience in enhancing health and social care practices. This central message set the stage for the three speakers as they candidly shared their personal journeys.

Stuart shared his experience after being diagnosed with young onset Alzheimer's disease in January 2022 aged 58. He reflected on the troubling signs he noticed starting in March 2021, including memory lapses and cognitive decline. Stuart went on to emphasise the need for individualised support for people living with dementia and the importance of treating each person with dignity and respect. Ultimately, Stuart inspired the students to approach dementia with compassion and understanding by sharing both the challenges and positive transformations he experienced following his diagnosis.

### A key message from Stuart

*"By treating those you will work with in your role as individuals, supporting and encouraging them to be themselves and do what's important to them, you will be able to help ensure they are not defined by their situation, but that they continue to live their best life possible."*



SDWG member, Stuart

Margaret, who was diagnosed with frontotemporal dementia at 51, shared her personal journey which provided a valuable insight into supporting people living with dementia. She highlighted the challenges she faced after her diagnosis and emphasised the importance of a person-centred approach in health and social care support. Margaret encouraged the students to prioritise understanding the individual behind the diagnosis and to foster inclusive, personalised approaches in their careers. Margaret concluded with a powerful reminder to always see the person before the condition, underscoring the importance of dignity and respect in care.



SDWG member, Margaret

### A key message from Margaret

*"As you prepare for your new careers, a key message I would give you is - recognise the individual, not their age or their illness. Listen to them and get to know them. Find out about their interests, their feelings, and their views."*



Marion, a former carer for her husband with vascular dementia, addressed the significant challenges and emotional toll faced by carers. She highlighted the complexities of dementia, including the changing needs of those affected and the distress carers feel in accepting help. Drawing from her experiences, Marion provided practical advice to the students, urging them to engage with family members and create a collaborative environment that values the carers input. Marion stressed that care extends beyond the home, emphasising the need for continuous communication and empathy in hospitals and care homes. In concluding, Marion commended the dedication of care workers and urged the students to treat individuals with dementia as if they were family, highlighting the importance of supportive relationships between professional and family carers.

### A key message from Marion

“Please remember that the family carer is trusting you and needs you to look after their loved one as if they were your own family. Think of the person with dementia as your mum, dad, grandma or grandpa and think how you would like them to be treated.”



NDCAN member, Marion

In conclusion, this event showcased the dedication of SDWG and NDCAN to incorporating the perspectives of individuals with personal experience of dementia into student training programmes. Their commitment to this cause highlights the significant potential for advancing education and fostering impactful change within the health and social care sectors. By recognising the insights shared by Stuart, Margaret, and Marion, the students will without doubt, be better prepared to improve their practice, ultimately resulting in better outcomes for those they will support in their chosen careers.



### **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 Voice Team, please email: [activevoice@alzscot.org](mailto:activevoice@alzscot.org).

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