Engaging Dementia Conference, Mullingar, Co. Westmeath, 8th and 9th May 2024 – a Volunteer's Perspective

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In early summer, on 8th and 9th May 2024, I volunteered at the Engaging Dementia conference in Mullingar.

It was my first time encountering the charity Engaging Dementia established in 1990 by Sr Mary Threadgold. Now 34 years old, this small organisation is especially known for developing the training method called <u>Sonas APC</u> to assist people living with dementia and to improve their life experience.

I volunteered at the conference because I had heard about it from a friend, was curious because it felt person-centred and I thought I could use my people and communication skills in a way that would help a worthy cause. I have a background of living with a person with dementia — when I was a child my grandmother Mary had Alzheimers; she was a central part of my family, lived with us, and my brother and I were close to her.

At this large two-day event, Engaging Dementia worked with a group of volunteers coordinated by Michelle on their team. Several of the volunteers joined the conference from the <u>Westmeath Volunteer Centre</u> and there were some volunteers, young people, who were training and involved in education in the area of dementia study.



Noreen, Elza, Janet, AnnMarie, Cate, Mary, Denis – some of the lovely volunteers at the conference.

I really enjoyed volunteering at the conference. I loved the variety of people I met and the atmosphere there. I loved the collaboration between organisers and volunteers, and the general feeling of cooperation and camaraderie in evidence among all different types of

participants from academics, health care professionals, people living with dementia, service providers and us as volunteers.

In a nutshell, I wanted to write this article to generate awareness about what I saw at the conference, to let people know about the sector of people living with dementia, those within the sector and the state of the knowledge, work and ideas generated from within this domain and space.

I believe we all know a person living with dementia and it is important and a great privilege to know more about their experience.

Some highlights include when some people living with dementia performed the original song "We Will Tell Everyone" at the end of Day 1. A Patient-Public Involvement group wrote the song in collaboration with Lisa Kelly and Carl Corcoran.

Performers included **Kevin and Helena Quaid, Gerry and Nuala Paley, Helen Rochford-Brennan and Carmel Geoghegan.** They had the stature of opera singers and performed with pride and pleasure for the rest of us – it was a very moving and emotional experience to witness this. These are amazing people – **leaders**, and are doing a lot of good for other people coming behind them and for their sector.

On Day 2 I also especially enjoyed the presentations from **Kevin Quaid** about **walking the Camino with a Lewy Body** diagnosis and the Irish Dementia Working Group members **Kathleen Farrell and Catherine Murphy, who presented on "Rights made Real".**

Among other things, they talked about their experiences in going to the hospital and encountering some staff that do not know what Lewy Body Dementia or even Alzheimers is. Kathleen shared: "I was terrified" (when she had to go in an ambulance to the A and E; she was worried that people would not know about her dementia or how to interact with her).

Kevin: "Is it a big ask? I don't think so." To the question about having one dementia nurse specialist or more who could talk with people/patients with dementia and with their family in hospital.

In conclusion, I was amazed at how well everyone worked together and at the warmth and complementarity of the energy. It was a lovely group of people and I think it had everything to do with the sector, with the fact that we were working with people with dementia. It all stemmed from that. The vitality, self-possession and nous of the **people there living with dementia** was a sight to admire, was inspiring and had great dignity within it.