

"We shouldn't be defined by our illness"



At the 29th Alzheimer Europe Conference on October 23-25 in The Hague, 945 people attended from 46 countries. The central theme of the conference was 'making valuable connections'.

Among the delegates were 36 people living with dementia and their family caregivers. These 'experts by experience' had an active and important role as chairs, speakers and participants in several sessions. They addressed clearly the

importance of not only hearing their voices, but also taking their ideas seriously into consideration. It is crucial, so they stated, that people with dementia are invited to be involved in the initiative, the design, the development, the practice, and the implementation of both research, policy and practice. This should be a close collaboration, a close exchange of ideas and knowledge in the whole process, between professionals and people with dementia and their families, not just 'ticking boxes'. They emphasised the importance of not just being a dementia-friendly society, but being a dementia-inclusive society. A society in which people with dementia are empowered and supported to stay active, use their abilities, find a way to live with dementia and experience a meaningful and dignified life. *"Despite the disabilities the dementia brings, still I would like others to engage with me in a respectful, appreciative and equal manner."*

The members of the European Working Group of People With Dementia (EWGPWD) organised an inspiring and impressive session, led by the chair Helen Rochford-Brennan. They shared their personal experiences and stories, live and in short films: about their search for a proper diagnosis, the lack of post-diagnostic support, the for others sometimes invisible struggles in daily life. But they also shared their stories about how they managed to find a new way to have an active and fulfilling live, their successes and contributions in research and policy, the support and friendship they have found in the connections with other peers. *"We all need to belong, to be connected."*

The mutual friendship and support is visible and beautiful to witness: when they help each other in telling the personal stories on stage, in translating for each other, in the jokes they share, in a wink, in a smile. They firmly state: *"We shouldn't be defined by our illness, we are still people."*



Unfortunately not unexpected, several participants with dementia stressed during the conference that the stigma they experience is still very strong. This struck me, that so many people are still stigmatised and thereby enabled to live their lives. There is a need to fight for human rights for people with dementia, to be treated with dignity and respect, to be listened to and to be understood. I felt their frustration when some of them emphasised how strong the significant misunderstanding is that dementia is only about memory problems. Especially people with young onset dementia and their caregivers often still need to convince others who don't understand their symptoms.

In the discussions about changing behaviour the misunderstanding and thereby maltreatment is one of the emotional topics. One of the attendees with dementia I talk to, asks the questions that are painfully true: *"why are there still drugs prescribed for the wrong reasons to people from which everyone knows now they are ineffective or even counterproductive and have severe side-effects? Only a small part is helped with these drugs and still, in many places, these are given to people."* She, myself, and more of the participants talked about how striking it is that so much more people, organisations and companies seem to be ready to change their approach and the environment when someone has another, physical, disability. *"Why isn't that the case for people with dementia who are telling us, via behaviour, there is something wrong. Because that is what it is: it's a way of telling us we do something wrong, in our approach, in the communication, in stimuli, in the environment. So the environment is not right or they need something. It is a way of expressing an unmet need, a feeling of discomfort. Is that what they will do to me too, in a couple of years when my dementia gets worse and I am only able to express myself by pacing around or so? Will they give me pills instead of someone trying to find out what I actually wanted to say?"*

It hurts me, I know it is happening in practice that people send signals that are too often misunderstood or not listened too. Everyone should learn to understand these personal, individual signals. We should all together try to make this puzzle until we truly understand what the person with dementia has to say, wants to express, and then we need to find a personal, contextual answer to this. The key lies in the inclusion, support and understanding of every individual with dementia, see the person and answer to their personal needs and wishes in the given context. Quality of life and wellbeing for people with dementia can only be reached when everyone focuses on individual possibilities of the person in relation to their loved ones and environment.

October, 2019
Josine Engels
The Netherlands