

European Dementia Carers Working Group (EDCWG)

The EDCWG, launched by Alzheimer Europe (AE) in 2022, is composed of current carers, relatives and supporters of people with dementia or carers with prior recent experience of caring. It's members come from national Alzheimer associations across Europe, and Alzheimer Scotland is represented by Barry Northedge with Elaine Deehan as the alternate member. Working Group members advise AE in all its work to ensure it adequately represents the interest of carers of people with dementia. Barry attended the Group's first face-to-face meeting in March 2023 in Brussels and has provided this report.



first meeting of the EDCWG

Remember 'The Verve' from the 90s? They knew what they were singing about; "The drugs don't work, they just make you worse"

The meeting discussed the impact of agitation and aggression on the well-being of people with dementia and their carers and sought to explore the effectiveness (or not) of the use of a variety of drugs to suppress these symptoms. Academics involved in research championed the value of high quality, person centred care as opposed to the use of medication to treat the symptoms of agitation and aggression. Professor Sube Banerjee from the University of Plymouth debunked the use of medication whilst extolling the value of person centred care, a theme which was supported by research and projects from across Europe.

How often is medication the first option rather than taking the time to get to know the source of the agitation?

As an example of this I spoke about a visit to my father-in-law, Tom, in nursing care, when he was particularly agitated, ill at ease with himself and everyone around him. His language might have been described as 'industrial' at best but staff chose to ignore his agitation rather than to try to get to the cause - they probably had too much to do to spend time on one resident. Tom was totally deaf in one ear and had a hearing aid in his other ear, unfortunately it had no battery so he couldn't hear a thing that was being said. No-one had thought to check this until myself and my wife (Tom's daughter) Margaret visited. Battery fitted, hearing restored and agitation abated without the need for any medication, which had been discussed, to quell the situation.

The Working Group went on to explore the application of AI to support the early diagnosis of dementia and whether such an intervention would be trusted. We considered Pattern-Cog, a project to develop a tool to predict signs of future cognitive decline in cognitively healthy people, people who currently show no signs or symptoms of dementia; and discussed both the potential and the ethical questions around using existing and new data to predict cognitive decline before symptoms occur.

We also discussed the trustworthiness in AI to use sensitive health data to be able to accurately create models or make predictions on the diagnosis and treatment of Alzheimer's disease, with particular reference to a project which is developing an online brain simulation platform for researchers - VirtualBrainCloud.

"The discussions and viewpoints explored and shared can best be described as fascinating. The EDCWG is well and truly formed and functioning. Membership is spread across 14 European countries and discussions are just about as wide ranging. I'm already looking forward to the next meeting!" - Barry