# Vienna forms a working group of people with dementia

Angela Pototschnigg, Austrian member of the European Working Group of People with Dementia, has joined a new dementia working group in Vienna. She tells us about the group, which is called "Über den Berg kommen", meaning "Turn the Corner".



I was about 57 years old when I noticed that something was happening to my brain. I had trouble concentrating, my memory was not working as I was used to, mistakes were constantly happening in my professional work and I needed much more time to get things done. The burnout that was diagnosed at first, soon turned out to be a misdiagnosis. I had to give up my job and retire early. In order not to fall into a black hole, I started looking for supportive possibilities: I was offered handicrafts, painting and singing - but these things never interested me before in my life. So, I know how difficult it is to find an adequate support, from someone who has a great deal of knowledge about dementia, and who uses and passes on this know-how to accompany affected people in their everyday life, so that a self-determined life is largely possible.

I can well remember what a bad mental state I was in, because it is hard to cope with this diagnosis. But I was lucky and in my search I came across a support group for people with

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dementia. From these experiences I know how great and relieving it can be to have conversations with other people affected. I can now pass on exactly this experience in peerto-peer talks that I have been offering since 2019 under the umbrella of Alzheimer Austria.



Based on the experience and feedback from peer-to-peer counselling, the idea was born to offer younger people affected by dementia and people, who have just been diagnosed, a platform for mutual exchange and joint activities. A further concern is to strengthen self-esteem and encourage people to talk about their own worries, needs and wishes.

"Turn the Corner" (in German "Über den Berg kommen") started at Alzheimer Austria in February 2020, with a lot of plans for the group meetings...

# Many activities are planned

Experts from all over Austria are invited to give us lectures in simple language on various important topics to inform about possibilities that can support us in everyday life and in special situations.

It's about additional forms of therapy apart from drug therapy, such as occupational-, physio- and speech-therapy, as well as psychotherapy. Subjects such as memory training, exercise and nutrition, support in using technical equipment are also discussed. We will learn how a preventive power of attorney or a "living will" can be drafted so that our self-determination isn't lost if we are no longer able to communicate.



Angela Pototschnigg

There will also be presentations on basic and human rights, on our right to assistance at work, and on protection against discrimination. A neurologist will speak on diagnosis and drug therapy. After the lectures we can get answers to our questions.

I think it is particularly important for us, to get knowledge and information about the topic of dementia, because this way we can learn to deal better with the disease and to develop strategies. That's exactly what I was looking for years ago, and I think that's what happens to many people affected by dementia!

Being part of this project means a lot to me. This is about us! Our perspective is valued and our understanding of dementia, with its many stumbling blocks, is supported by knowledge, information, exchange and group discussions.

### COVID-19 gets in the way...

There were four of us at our first meeting on 20 February 2020. I liked getting to know people who share similarities with me, and we were able to have good discussions. All participants were looking forward to coming back.

Unfortunately, the coronavirus and the lock-down intervened and a next meeting was out of the question, for the time being.

### ...but not for long

I was very happy when the activities at Alzheimer Austria were able to start up again, carefully, and on 18 June the time had come for our next "Turn the corner" meeting to take place!



That afternoon, occupational therapists were invited to inform us about the goals we can achieve through occupational therapy: The aim is to maintain our independence for as long as possible, to be able to maintain social contacts, and to prevent our withdrawal; as well as to make everyday situations clearer and simpler, and learn to manage stress. The question "What do you really enjoy doing?" is also asked in occupational therapy, because an important goal is to support us in things and activities that we enjoy.

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The next meeting after the summer break started in the third week of August, this time we were nine participants. A psychologist, the head of the Academy for Memory Training in Salzburg, gave a presentation on holistic memory training.

As many brain functions as possible, such as perception, concentration, memory, word finding, orientation and creativity should be stimulated, she said. I already have experience with it myself, because I've been doing memory training for about a year. For many, however, the topic was new. She gave us suggestions on how we can also train our brains in everyday life.

It's not about practicing things that are particularly difficult for us, to the point of exhaustion, but rather starting with what we enjoy and where our interests are going. I liked her advice to "be patient, indulgent and tolerant" with

our brains, because after all it still serves us well, plus we learned that stress and self-reproach damage our brains. Another thing I found really good to know, which she pointed out, is that a healthy brain also has its gaps!

## Alternating meeting types

I particularly appreciate the concept of the "Turn the corner" project where meetings with lectures and meetings for exchange and discussion alternate. I think that's very important and gives us the opportunity to get to know each other better and to learn from each other.

Johanna Püringer is responsible for the organisation and management of the meetings. Her presence at the meetings is useful to ensure moderation and a good process.



The Diplomatic Academy of Vienna dedicated its annual charity ball to the new Turn the Corner group, February 2020, Vienna

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