

ProMenz

Initiative by and for persons with forgetfulness

“I want to keep my smile.”

From the self-help group

The Society Background

Peculiar “mental blackouts” in everyday life, loss of orientation during vacation... Cognitive problems cause shame and a loss of security in persons affected and cause these persons to isolate themselves instead of their embarrassment being exposed in front of others. In addition dementia is linked with frightening visions of its final phase: Loss of intellect, memory loss, helplessness. A dementia diagnosis seems to mean the end of life. This makes an open confrontation even harder for persons affected and stigmatises them.

Examples of “dementia ambassadors” like Helga Rohra in Germany demonstrate that the diagnosis can mean the beginning of a new, meaningful and successful life. Persons affected need information and therapy, but most of all potential—oriented support: Understanding, encouragement, attention for their potentials and the possibility to activate them in the community. Various studies show that there is a lack of such offers for persons with early phases of dementia.

The ProMenz Initiative

Monika Natlacen and Reingard Lange in 2014 were the first to conduct group interviews with persons with beginning dementia in the German-speaking region. Following this they started a supported self-help group in February 2015. This group has soon gained a stable core and has developed the concept of “Supported Self-Help” by Michaela Kaplaneck further. The group has named itself ProMenz and chosen the subtitle “Persons With Forgetfulness”. In the second year members were already willing to publicly lobby for more understanding, for support and for a potential-oriented view of aging and “forgetfulness”. Self-help developed to public self-representation.

ProMenz is networking internationally with the German association TrotzDemenz, the European Alzheimer Conference and its Dementia Working Groups.

So far ProMenz is kept alive by voluntary support by all persons concerned, by donations and the offer of rooms and material expenses by co-operating organisations; at this time they are Alzheimer Austria, The Kardinal König Haus and Caritas of the archdiocese of Vienna and supporters like Cornelia Bast.

ProMenz defines its concerns as follows:

1. To have a future: To find value in this way of aging, to find purpose, to develop attention towards oneself, learn to enjoy life with forgetfulness
2. To have a protected sphere: Finding understanding and acceptance, exchanging experiences, laughing together
3. To learn from each other: Everybody has different potential and different ways of coping
4. To influence society: Persons with dementia/forgetfulness realize their rights, encourage others – also younger persons -, campaign for an environment that is forgetfulness-friendly, as well as individual aid to persons affected and their families and caregivers.

*"I haven't been here in such a long time.
I have totally forgotten that I suffer from dementia."*

Supported Self-Help

Ever since February 3, 2015, self-help meetings take place every other week (except during vacations). Persons attending are handicapped in managing everyday life by cognitive deficits, with a diagnosis or suspicion of dementia, and are interested in exchanges with others.

Supported Self-Help means management of the group by persons affected. Their demands and their perspective are the focus of the group. Support persons render services and assist: They don't program the meetings. They encourage, document, secure and support the process of discussion and work in the group.

Meetings provide a protected and confidential sphere for participants. They can discuss their thoughts and feelings freely. They can develop ideas for a good life with forgetfulness in spite of dementia. The slogan is: "We accept our weaknesses and enhance our strengths. We learn to be careful and tolerant towards ourselves and others. For participation we need understanding and support."

ProMenz is open to new developments and looking forward to new members. For the time being it is the only group of this sort in Austria and wants to support foundations of additional ProMenz groups.

"She is brave enough to show it."

Self-Representation and Networking: External Impacts

Participants found many possibilities to help themselves and others. They especially wish to have an impact on society. They have developed a procedure to cope with the many requests that come from outside the group: Requests are discussed in the group and participants chose the ones they are interested in. Supporters then accompany them to, from and during the chosen activity. Reactions by others are often challenging for persons affected: "Oh, so you have dementia?"

Members have been active

- as the first and only persons affected in the development of the Austrian Strategy for Dementia 2015/16
- on the podium in discussions during professional events and anniversary events (Caritas of the archdiocese of Vienna, VertretungsNetz (a network of organisations supported different groups of handicapped persons))
- at press conferences of Volkshilfe and Caritas of the archdiocese of Vienna
- at the artistic research project D. A. S. (Dementia Arts Society) of the University for Applied Art, Vienna, led by professor Ruth Mateus-Berr
- at the research project WAY.KEY of the Technical University, Vienna

Members of the ProMenz group have demonstrated that people with dementia are willing and able to represent themselves publicly. They are positive role models and authentically counteract stigma and popular fears in connection with dementia.

At this time the group is founding an association and develops statutes, processes, content and the program. The board will consist of persons with forgetfulness and supporters. The ProMenz association shall provide the organisational framework for applying for financial support and securing self-representation for the future.

Contact with “dementia ambassadors” like German Helga Rohra or activists in the Alzheimer Europe Conference is an important motivation and aid for the challenging activity of self-representation. Group member Bea was the first affected person from Austria to take part in the Alzheimer Europe Conference in 2016. The group wants to continue the stimulating participation in international exchanges.



“Forgetfulness is almost modern these days.”

What Makes ProMenz a Social Innovation?

- The focus is on a **target group overlooked** so far: Persons with beginning dementia.
- The basis was networking and empowerment of persons affected, this required support persons. In the meantime persons affected agitate for the improvement of their situation and their public image. Depending on the situation they ask for support.
- The persons affected are **pioneers for Supported Self-Help** for people with forgetfulness in Austria.
- They are also the first to **publicly agitate** for their demands in Austria.
- They combine individual, collective and sociopolitical goals:
Strengthening of persons by Self-Help: Experience acceptance, laughing together, learn from each other.
Forming an association in order to secure the future of the initiative.
Wide-ranging public relations work for recognition of this form of ageing and against stigmatizing public stereotypes.
- ProMenz is not a financed service, but **a sphere that the persons affected gradually make their own**. There is currently no model for this kind of participation in the German-speaking region.
- We perceive ourselves as an **initiative under development**. In order to scientifically evaluate our own learning experiences in developing self-help and self-representation a research project will be started in 2017, and its results will be made public. The main topics will be:
How can support persons continually do the necessary work and at the same time orient themselves without compromise towards the intentions and possibilities of the target group?
How can flexibility be assured in order to be able to react to unforeseen demand for support?
How can the relationship with families and caregivers of affected persons be improved?
- We are **networking with social and health-organizations** in Austria as well as **internationally** in order to stay innovative.