

Helga Rohra...

*Ich bin dement. Na und?
I have dementia. So, what?*



A personal experience ... Living with dementia...

“A letter to you, my friends and to all of you who have been touched by dementia”, Helga Rohra.



Almost 4 years have passed since I got that *diagnosis*: “You have got a quite seldom form of *dementia*. It is called Lewy-Body dementia”. Today I realise that life with such a diagnosis is a challenge. It is a daily challenge for myself and all those around me.

Imagine...

- I was a person in a highly demanding profession. A translator, who spoke 5 foreign languages. Someone who was very active in her early 50 ties.
- I took care of my son and my 2 cats.
- I was very involved in social activities.
- I dedicated my time to helping refugees, especially youngsters seeking asylum in Germany and handicapped people.
- I enjoyed life.
- I was respected and admired. My neighbours knew I could always give an answer.
- I was a very open-minded person.

My life was okay

And all of a sudden everything changed...everything became different.

- I forgot my vocabulary, even in my mother tongue.
- I got lost.
- My visual hallucination became my best friend. My fatigue permanently present.

My son is my assistant. My cats are my best companions. Social activities are a burden. *Dementia* is something others are afraid of. They know just a bit about *Alzheimer's disease*. They avoid me. They feel embarrassed. What can they talk about with someone like me? They think I do not understand. They have in their mind a certain picture of people affected by dementia. The press is, in part, to be blamed.

It was a long way. A journey to my new self. I know that a dementia is more or less a clinical diagnosis. The way I deal with this “handicap” is to fight. I started a special programme. New way of diet, of daily physical exercise, mental training. I am actively speaking up on behalf of all of us affected by dementia. We are in the very beginning. Medicine/tablets are important, but even more important is the way you deal with your handicap. Believe it or not you can make the best of it.

- Helga Rohra,
Munich, Alemania.

Life is beautiful even with dementia!

I attend German and European conferences. I tell them to forget what books say about cognitive impairment and to instead please realise the still existing abilities people with dementia have and promote them!

I tell doctors, carers, authors to talk to us, to listen to us, to involve us in their decisions about new programmes for people with dementia. We know best what we need, what burden our family carries day by day. I speak up for us all: Involve us, believe in us.

Living with dementia is a new life. It is a challenge for you all and also the chance to face dementia together. ■



*Helga Rohra.
From Munich, Germany.
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