



My Name is
Dagmar,
57 Jahre old,
Married , 1 Son and have LGMD
(sub kind name not known).

Although symptoms of the disease (frequent stumbling and many falls) were present as I was a child, it took 30 years – despite many visits to the doctor – to be diagnosed. My muscular disease usually gets worse and worse. But I'm fine with it, even though I've had to use an electric wheelchair for 9 years. Before that, I was a pedestrian – for many years with Nordic walking sticks.

I am most annoyed or puzzled by reactions from other people:

1. Our disease is often confused with MS (multiple sclerosis). Our disease is a disease of the muscles and MS is a disease of the nervous system.
2. Many do not perceive my husband as my partner but only as my companion. "What, you have a man?" "What you have a child?"
3. My husband is being talked about my self the third person, even though I am standing next to him.
"Sorry, you can have a normal conversation with me!!!"
4. A neighbour: Don't you even want to go to the handicapped workshop to work there? You're bored all day, aren't you?"
"Hello, I have completed a banking apprenticeship and worked for a bank for 27 years and receive a full disability pension and I have various hobbies. "
5. As a young woman I stumbled and fell in the pedestrian zone in the morning. A lot of people stopped and watched. One of them said, "Look at the old lady, already drunk in the morning", and everyone laughed, nobody helped.
We have a fluctuating and unsafe gear, stumble fast at the slightest bump and fall.

I could describe many more experiences, but that would probably fill a whole book.

Conclusion: We are normal people – we lack nothing except muscles – and that's how you should behave towards us.