

More knowledge brings more benefit to patients!

Diagnosed with MS and then ...

When I got my diagnosis in 2005, I didn't know a lot about multiple sclerosis. I was absolutely uninformed. Why should we think about diseases if we are not ill? This was how I thought... Life was good. Until MS appeared.

My questions were simple, although difficult to answer: I needed information. Why do I have MS? What will happen? Will I die? Do I need a wheelchair? What therapy is right for me? What else can I do? What is the cause of my MS?

I was depressed, frustrated, a result of being innocent and not knowledgeable. And some people, like my family, asked me questions I could not answer. I asked a lot of questions at the hospital. The doctors gave me some information, but not enough to understand what was really happening. The only thing I understood was that it was serious. I had no knowledge about relapses, side effects, therapy, rehabilitation and my rights. Most brochures were for advanced patients, not beginners, not helpful; I decided to do some research. I started my search online. And found things. I asked other doctors, found some other patients with MS on social media. Then I talked with my health insurance about my rights. Doctors were not very clear in their communication about MS. I didn't understand them. It was necessary to find easy and understandable information. I focussed on patient groups, looked for sites about patients' rights. I started to collect all that know-how and started to sort out information, the good vs the bad. I realised how important patient information is. And I noticed that there was not much understandable and useful information for patients.

From patient to patient activist

Patient-level information is important for good decision-making, to understand the gobbledygook of doctors and the law. I continued my research and learned a lot. I started to cooperate with a German women's magazine, blogging about my life with MS. I told the readers about myself, my MS and what I'd learned. This was my introduction to becoming a Patient Activist. I'm still blogging, in German, at <http://leben-arbeiten-mit-multiple-sklerose.blogspot.de>. My wish is to have more information for patients, because their health is the only health they have and they have to make decisions that make sense for them. This is possible with enough information and I share this concept via my blog, social media, as a speaker at congresses, in discussion panels and more. And I continue to find more information, study courses and continue learning.

Patients have to learn. Just like doctors, pharmacists, governments, health insurance companies. We need to share an eye-to-eye perspective, we have to talk together. Today I'm informed and I like it! I make better decisions, I do more for my health living with MS. The conversations with my docs are better. We've found a good way of working together. I appreciate that. As I always say, more knowledge brings more benefits to patients, so take the chance and learn. When I got my diagnosis in 2005, I didn't know a lot about multiple sclerosis. I was absolutely uninformed. Why should we think about diseases if we are not ill? This was how I thought... Life was good. Until MS appeared.

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