

Marie's story (from Czech Republic)

Hello to everyone who struggles with Functional Movement Disorder.

I'm 38 year old woman and my problems started all of a sudden one day in October 2012.

Two days prior to that, I had terrible headache, my legs were heavy and felt like I was going to get a flu, which my 4 year old daughter just went through. Nevertheless we needed to buy something and went to the shopping center. There at first I thought, that I stumbled, did few more regular steps and stumbled again. This happened few times. Then my legs got paralyzed in my knees and I couldn't straighten them up. It was really difficult to walk, I looked like a child with cerebral palsy. I felt worse and worse, had terrible pressure in the back of my head.

My husband rushed me in to the hospital. The doctors carried out an MRI examination, CT scan and two days later a lumbar puncture. At that time I could walk only few steps in the paralyzed position, still had terrible headache, my toes were bent under my feet, I had all kinds of muscle spasms and jerks, I had constant feeling like I had jackhammer in my legs, and in some ways I lost communication between my legs and the brain, I was very sensitive to light and sounds, had difficulties with speech and concentration. We were very scared, because it looked like something between stroke, multiple sclerosis, inflammation of the brain, total breakdown of CNS. As well as the tests above, the doctors did all kinds of blood test, EEG, eye examinations etc. All results came negative, except that I had autoimmune thyroid disease that I didn't know about so far, but which couldn't make such neurological problems. I was put on high corticosteroid treatment. I felt extremely tired, but everyday my legs and torso started to straighten up a little bit and could do few more steps. They started rehabilitation with me, I was learning how to use my legs and how to walk like a little child again. I was released from the hospital after two weeks with corticosteroid pills for three more weeks. The doctors couldn't give me any clear answer to what happened. They didn't find any organic problem in my body. They told me that sometimes it happens after tremendous stress and kept asking me, if I went through something like that. It was for the first time in the hospital, that the doctors mentioned, that it could be a functional disorder, but didn't explain to me more clearly, what a functional disorder means. They offered me only psychiatric help and I felt very disappointed and helpless. They released me from the hospital and told me to come for a check up in two months or earlier, if my problems didn't go away. They told me to wait, that neurological problems sometimes take time before they can be properly diagnosed.

And my problems didn't go away. I kept asking the doctor, but his answer was always, we did all kinds of tests and there is nothing there, believe me it's only in your head, go to see psychiatry. Every time I stepped out of the doctor's office, I was so frustrated. I felt so humiliated, how could my problems be only in my head? I was not making them up, I couldn't walk, not talking about other symptoms going with it. My problems were real.

At home I had 4 year old little child, who needed her mommy to take care of. And the mommy couldn't take care of herself. I could do few steps around the house, but that was so exhausting for me, that I wasn't able to do anything anymore. I thank God that I have such great family. For few months there was always somebody living in our house and helping us. I don't know what I would have done without them.

Of course my husband was helping as much as he could, but he had to go to work and couldn't take days off all the time.

Naturally I am a person with positive attitude. From the first day it happened, I told myself that even if I had to be on a wheelchair for a year, that I would walk again normally and I would be healthy again. It appeared to me like something happened to me for some reason, but that this was not supposed to be my life and I will make it again. I felt really motivated, not only myself but especially my little daughter, my husband and my family. I felt confused, frustrated but never depressed from the situation. I never even asked why me. Because my husband doesn't give up either and we both couldn't just, after seeing me battle every day, accept the theory "there is nothing wrong with you", we started the journey of looking for and going to different specialists from immunology to Parkinson specialist etc. All results came negative though. They didn't find anything again. Most of them said, that the mostly it looks like multiple sclerosis, but that for sure, it would show on MRI or from lumbar puncture. Of course I felt scared because I knew, that in this case, I would need to start the proper treatment as soon as possible. Than one neurologist gave me recommendation to the special and the best clinic specializing on movement disorders. Just like everywhere, there was a long waiting list, but I was very happy, that they accepted my case and will see me. I put all my hopes into that. The first visit I had in April 2013 and of course, because it is a big clinic and plus they wanted to do their own new examinations, it was in October 2013 till I got into the right hands of neurologist specializing on Functional movement disorder. After a year I finally was diagnosed!

Finally I had wonderful but really wonderful doctor, who sat down with me and explained everything to me, what is going with me. Finally I had a doctor who believed me, who said yes your symptoms are real, you are not making them up, there is more people like you, it is not in your thoughts, your brain under some circumstance doesn't work like it should. What a relief it was! And also she said that there is a way out of this and we will teach you how to get out of that. The doctor gave me these wonderful websites as well, which could give me answer on a lot of my questions. I was so so happy!

Before finishing, I should make my story complete and go back in time. The worst as far as my physical problems were for me first four months. I had all my symptoms, was very exhausted and literally was trying to do few more steps every day. To go around our house, I was able to go with canes after two months. Probably just like everybody bedridden for most of the time, I spent a lot of time thinking and going through my life and myself. When the doctors for the first time mentioned did you go through any big stress, I said "no - we were just moving and went through few difficult things, but through things a lot of people go through or they go through much worse things on daily basis". I always thought that this could happen to people, who go through stress like death in the family, car accident or that big type of a stress. But when I went deep into my mind, I realized and had to admit, that the year before I went probably through a big stress too. Not the one time shocking one, but a more constant one, which probably sucked all my energy out of me and resulted into physical problem. The year before my daughter was three times really sick, two times ending in the hospital, we were selling our house, which I was very emotionally attached to, plus instead of normal buyer seller partnership it went to a half a year fight, than physical moving from house to apartment and also after a four year maternity leave I started to go to work again. Now I see it clear. No wonder I totally collapsed. But strange for me was, that it

happened two months after all that stress. At the moment, when finally everything was fine, when we were settled, I felt great in my new job. Of course now I know how our body and mind works. It always happens after it can take a rest. Then it starts to think of itself and says "I had enough".

So in February 2013 when I finally occasionally started to feel like myself and was in a little better condition physically, I decided to put on the recommendation of doctors and go to psychotherapy. I wanted to do anything that could help me. My health condition was taking too long without knowing how long it will last and even though I didn't feel depressed, it was difficult on my psyche. I found a wonderful doctor, whom I was meeting every week for eight months. During that time we went through so many things in my life, we went so deep into my mind and soul. I am so grateful to her for leading me into such wonderful thoughts, for guiding me to paths, which put my life in order, for finding in me strength and self-confidence. Now I really know who I'm and what I want in my life. The relationship with my husband got into a different dimension too, even though we loved each other even before. And of course I'm also very much thankful, that during that time it was the person, to whom I could tell how I feel and who would listen, because nobody wants to listen to complaints all the time and also I didn't want to burden my family or friends even more. The situation was hard for them as for me.

Mentally I never felt better, never had more peace with myself. Still I had physical problems. Not as much and not in as such strong way. But it was still here. Difficulties with walking, headaches, other symptoms...and especially fatigue, that was and is the worst of all. But I learned how to divide my strength during the day, how to split my energy, so I can take care of my family again, which makes me happy, even though I'm very tired. Little by little I started to have healthy days also. But my problems still would come and go. I detected some patterns, like if I overdid something that day, if there is change of weather, also my woman's hormones affect my condition or viruses. But sometimes it appeared and still appears all of a sudden out of nothing at moment when I feel great, the least I would expect it to come. So during spring 2013 I started to feel better, but then my condition got worse during the summer again. I had total heat intolerance. Even though I used to be a person who loved hot weather and sun tanning. Somehow it was probably stress on my body. After that I got better again. It hit me strongly in the fall 2013, but I already had professional help by then.

In October 2013, as I mentioned above, I finally got diagnosed and together with my neurologist we went through my whole disorder experience, drew some time chart of my "attacks", and the doctor told me to be prepared, that even though I will feel better and better, that the attacks will appear probably few more times. She assured me, that there is really no damage in my brain, that the brain only needs to learn how to work the proper way again. As you already know about the hardware and the software. This assurance itself helps a lot, this way there is no need to panic, there is the only need to calm down and patiently wait till it goes away again. The doctor told me about distract techniques, which helped me a lot too. We found out that my biggest problem is that my symptoms appear mostly when I physically overload myself. My biggest issue is to find balance between activity and rest, so my body and mind doesn't get into the stress, which is hard sometimes. Naturally I am an active person and when I feel good, I have tendency to do more, walk further, go for trips, just live as a healthy person. And sometimes when I overdo things, I have to pay high price for it. Sometimes the problems appear out of nothing and no distraction, nothing helps but time, but that goes with the diagnosis as well.

But I'm doing better and better. Right now my biggest issue is fatigue, which I'm trying to break with slowly raising exercise. My symptoms appear now probably every three weeks and since last November I had one bigger attack. That is always very unpleasant, because it takes few weeks before I get in shape again, but also it slows me down and gives me opportunity to think over, what did I do wrong and not to repeat it next time. Also now I know, that something big happened in my brain and it takes a lot of time before it gets in normal functioning. It cannot be fixed in three weeks like a fractured arm.

Of course it is a long road, one and a half year now, and I have still some way to go, but I see that with patience, self-control and great support of my doctor and family I strongly believe, that one day I will be completely healthy and without symptoms.

Even though I've been through a lot and it was not easy at all, I'm very thankful to what happened to me and I take it as a gift. My disorder thought me a lot. The most of all I learned to be patient and stay positive. It has changed and enriched my life in so many ways. Nothing happens without a reason, even though we may not see it at the beginning. The most of all I am grateful for my life, I appreciate every day and all the ordinary things, which I used to take for granted, including my health. I appreciate every step in my life.

Everybody, who is ill, needs to find a good doctor and also their own way, how to get their life healthy again. Whoever is reading these pages on this website, has half work done – found the doctor! And now there is only the other part of the job left. It is worth the work.

At the end I would like to thank to my wonderful doctor who led me to a successful happy end of my story and also to all doctors, who do research on this diagnose, who take care of us and who put together this great website, where we can not only find answers to our questions, but also can share our stories, which is so important to all of us.

Wishing you a lot of healthy days!

Marie