



I am Elli Närhi and I have dystonia, generalised dystonia. It's the most difficult form of dystonia, but I am tempted to say I now have only cervical dystonia due to DBS.

I got dystonia, when I was 31 years old, at 2004. My oldest son had just got out of hospital two months before after a very severe situation. It was a miracle, that he survived and I was overwhelmed by joy. I got pregnant again. But then first my head started to twist backwards and towards the right shoulder. I had a lot of pain. At first I just thought it was the stress over my boy's situation. It didn't get any better and everybody was just helpless.

I live in a small town in the Northern Finland so nobody knew, what dystonia looked like. At the worst I could just lie down and my body would twist in violent cramps. People who came to see me was terrified and some cried.

Finally I got the diagnosis. At that point I could hardly walk. The doctors told me, that the only effective treatment was botuline-toxin. I had to make a very difficult decision. There was no way I could take care of my unborn child and I had already two very small boys, they were only three and one and a half years old. So there was not much choice. After that I got botuline injections, the amount of botuline was high and I couldn't hardly walk without help.

Then came an extraordinary chapter in my life. I was found by a documentary film director and a dancer. They had seen me in an art happening. I used to do many things with my boys though my condition. They rang me one day and proposed we would make an art project. It became bigger, along came also a photographer and my own ceramics. But nobody was more amazed than I myself that I agreed to dance in public and actually I learned to enjoy it. It became a project called "ELLI – The Cross Art Documentary". I was all over the press, mostly local but also in publications covering the hole Finland. This is how I spread the knowledge of dystonia.

People were very moved by the performance. One part of the documentary went abroad too and it have won a couple of prizes in some art exhibitions. This Documentary was made in 2009 but still people remember it amazingly well.

One day last year my doctor said: now we are putting you in line for Deep Brain Stimulation. She had talked to me about it years ago, but then it wasn't so safe to do it in Finland. There was not experience with patients with dystonia. But now there is. I didn't have to think about it more, I was ready. The neurologist in the hospital said, that I was the perfect candidate for the procedure. I had that kind of dystonia and I was quite young and healthy. So they took me to their patient, I was operated 10 months ago.

Now about 50-60 % of my symptoms are away! I must say I got a new life. It is heart breaking how genuine happiness people feel for me. Many people come to me and remember me from the Art Performance and they are so happy for me. And people with different kinds of disabilities are happy for me too. Of course Northern Finland is a small place so there are no other patients with dystonia who has this DBS-device. So I can bring information to people, but also be the sound of reason – not everybody gets help from DBS. To those who can't have that help I can be shoulder to cry on. Now the future is open in a very different way. I am going to study a new profession, I can't be a ceramic it's too hard physically. I want to help other people hopefully through art. I dream of being some kind of art therapist. It may sound funny but I have noticed that sometimes I can bring joy simply by being so healthy looking and smiling. Just last week my son looked at me and asked: "Mom why are you laughing so much at all this silly things?" I thought about it and I think it is thanks to the DBS-device that I have more to give. Not all the energy goes to the decease anymore.

I am active within Finnish Dystonia Association since i got dystonia. I am helping people thinking about the surgery or living with DBS, after operation. We would like to expand peering in Finland and if we get the award, we can open a new teleonline for DBS-patients and print some new leaflets for promoting DBS in our country.