

Edgar Stene Prize 2011

How exercise improves my life with a rheumatic disease

Lill Due, Norway

"Pas de chat! Stretch! Discipline!"

My French ballet teacher was strict. Strict and beautiful. She walked around with a stick and pointed at our feet if they weren't perfectly stretched out.

- "Stand up straight! Perfect!"

I worked out as much as possible as a child. When I danced I entered my own little world. My body lived a life of its own as I practically flew across the floor, "pas de chat", in my pointe ballet shoes. I was flexible, elegant, lean and strong. I achieved a fabulous self control and discipline. I needed to be in control of every nerve and muscle in my body to have the balance and strength to dance.

When I was 18 years old I danced as Cinderella with the Swedish Royal Ballet. When I was 19 years old I had become an ankylosing spondylitis patient living in constant pain. "Yes, you should be able to live your life as normal," the doctors told me. "It's important to work out so your back doesn't stiffen up. Ankylosing spondylitis can cause the spine to fuse, ruining your joints. The worst case scenario is surgery and prosthetic implants". They told me all this, but I didn't want to listen. I wanted to dance; to dance away all the pain and stiffness and the scary words. I kept on dancing on my good days, but on bad days I had to stay in bed. What about my future - education, work and family? "Try to live as normal," the doctors said. "It's important to exercise, but ballet isn't suitable for you anymore. You cannot become a professional dancer, but it's important to stay strong and flexible so that you don't stiffen up".

I worked out in the pool and went to physiotherapy. My life was turned upside down, but I could still move around. I danced in the pool. I danced on the inside. But I also cried when nobody was watching. Even so, I still had faith. I hoped to one day be pain free, to have my old life back; to walk without a limp, to dance, to live... without the pain.

"Unfortunately, there's no other way. We have to replace your hips", the doctors told me at the age of 24. I couldn't quite grasp the fact. It was as if someone had hit me in the face. Hip replacement, prosthetic implants? Cutting into my muscles, hacking into my bones, inserting steel into my body? What about my ballet, was all I could think about. Up to that point I hadn't quite given up, but now...

"It's important to have physiotherapy and to exercise", the doctors told me after I had my surgery. All I wanted to do was to stay in bed forever. "What's the use, I won't be able to dance anyway," I thought to myself.

As I was standing there, in the hallway at the hospital, I felt depressed, anxious and scared. "Who am I now? Am I still the same person now that I have this disease? Am I still the same little ballerina who was so flexible and elegant and who could fly across the floor on the points of her toes?"

Standing in the hospital hallway, holding on to my walker, it was suddenly as if a French voice was talking to me: "Pas de chat! Discipline! Stretch! Concentration! Keep it up!" I could almost sense the smell of sweat from the ballet room, and a soft tap from her ballet stick on my legs. I remembered how I always kept dancing, even when my toes were sore and bleeding. I closed my eyes and all of a sudden I knew that I was still the same person. I started to walk, one slow step at a time, and every nerve and muscle in my body obeyed, just as they did when I was dancing. Discipline! I practically flew down that hallway with the walker. Inside I was Cinderella dancing, on the outside I was a young woman with brand new hip implants.

With my newly discovered way of "dancing" I was inspired to not give up. I could feel that I was gradually gaining control over my movements. The pain decreased after a while. And even though it was painful to move around, with exercise and use of the muscles that had been severed, I could put more and more pressure on my new hips. I could walk again! Before the surgery I couldn't walk, but now, after months of physiotherapy, I could "dance".

Inside me I'm still dancing ballet as I do my exercises in the pool or with the physiotherapist. Without the self-discipline and self-control the ballet had taught me, I might have given up. But I will always keep on dancing, at least in my heart, even though I have a chronic disease and artificial hips. You can't give up when you are in this situation, because if you do you will just get worse – become weak and stiff. You have to move, to find new ways to use your body so that it will function as well as possible. I'm still Cinderella; I'm just dancing in a different way. I dance my own "pas de chat"!