



## **What it really means to be paraplegic and how I deal with it on a daily basis**

Swiss scientists recently developed a robotic system that enables a paraplegic person to walk again by bypassing the spinal cord lesion, using electrodes to send electrical impulses from the brain to the spinal cord. This news has been praised by many in the media as THE long-awaited solution.

When people think of tetra- and paraplegia, they immediately think of not being able to walk, and that is often the end of it. I do not blame anyone, as I was quite ignorant on the subject myself before I was personally affected by this disability.

It may come as a surprise to you, but being able to walk is not the most important thing for many of us. We are concerned about neurological problems with the urological system, bowel management, chronic pain, sexuality, blood circulation, bedsores, and so on.

I am particularly touched by the fact that so many doctors have only a superficial understanding of the complexity of spinal cord injury, and that is what prompted me to write this article.

Having made the choice to convey positivity and motivation, I have never before delved into this subject for fear that it would be perceived as complaining. I am going to speak objectively, so that those interested in the subject can understand a little better and approach it with fresh eyes.

I am going to talk about the observations and experiences I have had myself, but which are very probably similar to those of other spinal cord injury victims, whether tetra- or paraplegic.

Let's start at the beginning, the start of this new stage of life, waking up after my accident. A fall from the trapeze while I was a circus artist caused a rupture of the spinal cord at the level of the tenth and eleventh thoracic vertebrae, as well as a head trauma. I was told I have full Asia A paraplegia.

I cannot feel or move my legs or pelvis voluntarily. When I am lying down and cannot see them, I have the sensation of having only a torso with two arms and a head.

The first time I could sit up, three months after the accident, I rediscovered my legs like old friends I had not seen for ages. I looked at them and suddenly a surge of joy and hope crossed my mind: my

legs have moved! Amazing! Maybe I am recovering, maybe the paralysis was only temporary?

False hope. Then I learned a new word: spasticity. It is when the parts of your body that are no longer connected to the brain because of an interrupted nerve connection in the spinal cord start to move on their own.

There are two types of paraplegia: flaccid paraplegia and spastic paraplegia. In my case, spasticity is expressed by three types of muscular contractions in my pelvis, stomach, legs, and feet, i.e., the whole area below the spinal cord injury. These involuntary muscular contractions vary in intensity throughout the day and night, and when they become particularly strong, they represent alarm signals for other disturbances going on in my body that I do not feel directly.



Since becoming a paraplegic, I do not like to go barefoot. The fact that I cannot feel my feet makes them vulnerable, and I have often hurt my them because I could not feel that they were stuck somewhere or that they were rubbing on a rough surface. What is more, when I touch the skin of my feet lightly, or simply when the shower water runs over them, it causes that famous spasticity. The legs contract completely like a cramp and sometimes the calves start to shake. This is another type of spasticity. If I happen to have injuries on the part of my body that I cannot feel, which sadly happens quite often, there's spasticity by contraction or jerking. Muscles contract violently, at an irregular rate. Other triggers for strong spasticity are, for example, having a bladder or bowels that are not completely empty, or when I am menstruating.

The spasms are accompanied by chronic neurological pain, which translates into three types of pain for me. Firstly, there is the sensation of receiving electric shocks, a bit like when you touch an electrified cattle pen in the belly and the paralyzed upper thighs and this happens several times a day or hour, depending on the period. Then there are the pains I feel like a wound, as if a knife had been stabbed into my body in the area where my chest meets my legs.

Then there are these pains on the skin, as if the superficial layer of my skin had been torn off, in the transition zone between normal sensitivity and paralysis. These last two types of pain are continuous and of varying intensity.

I manage to reduce pain that feels like cuts in the flesh by pressing my fingers very hard on the most painful point and massaging my internal organs with strong pressure. This is what I do in the night

when I am trying to fall asleep... only to be awakened again by the next cycle of spastic contractions and severe pain. I then start massaging again, and so on.

For the hypersensitivity of my skin in the transition zone, I manage to alleviate some of it by wearing thick, tight bandages over the skin to prevent the pain being triggered by rubbing clothes. It also helps to coat these parts of my body with anesthetic ointment.

When the spasms occur in my belly, it causes pain that is a mixture of the two types of pain explained above. What is particularly humiliating for someone in my situation, is that this strong spasticity also affects my bladder and causes what you can imagine.

It is one of the symptoms of my disability that is the hardest to live with, and it has taken a lot of mental work to regain my self-confidence despite the problem.

You may be beginning to understand that a spinal cord injury does not just affect your legs. Your whole abdomen is affected too, and depending on the height of the injury, other organs might also be affected.



And then, of course, there is the big question we often ask ourselves but do not dare talk about... What about sexuality?

The genitals function normally, but without conscious control and without connection with our brain. Most sufferers can no longer feel their private parts. But often the nerves below the lesion in our spinal cord are still intact. Physiological reactions or spastic contractions then occur when physical stimulation is applied.

I think that for a woman with spinal paralysis, it is less painful to adapt to these profound bodily changes than for a man, who is generally expected to play a more active role in this respect.

I am lucky enough to share my life with my husband, and the love we have for each other has enabled us to compensate in part for these deficiencies and find a new way of expressing our sensuality. Our relationship is very enjoyable, enriching and fulfilling, despite the absence of normal

bodily reactions.

Among the organs affected, is the digestive system. With part of my intestines paralyzed, I have to conscientiously manage the quantity and quality of the fiber I eat. Too much fiber creates an obstruction, while too little also prevents the intestinal tract from functioning properly. Mechanical means are needed daily to ensure proper evacuation. I spend over three hours a day doing enemas and my bladder must be catheterized very regularly, as my sphincters can no longer be controlled normally, by my willpower. As a result, I had to learn to find alternative solutions to this problem.

Repeated catheterization makes us highly vulnerable to cystitis. This is a recurrent problem in spinal cord injury patients. To avoid these bladder infections, I would have to drink a lot, but with the above-mentioned concerns (spastic bladder), I limit the amount of liquid I ingest at public events or when I am out and about, so that I can feel at ease in my social life.

Dietary control is necessary to regain a little more well-being in my daily life. With the neurological disturbances caused by my disability, certain foods can irritate the nerves in my intestines. I therefore avoid anything containing small seeds, the skins of fruit and vegetables, strong spices and foods containing too much indigestible fiber for me. I also avoid coffee and anything containing the same type of stimulant, such as black tea, green tea, or cocoa. These foods cause me not only heart palpitations and tremors, but also increased spasticity.

In my case, in addition to this food control due to my paraplegia, there are food intolerances and the fact that I have lost my sense of taste and smell as a result of the head injury I sustained in my accident in 2007. I am sure you can understand that I do not eat for pleasure, but out of necessity.

Nevertheless, the feeling of hunger is always present and it often manifests itself more strongly after my sports training. I listen carefully to my body to give it the nutrients it needs daily.

When it comes to chronic nerve pain, the most effective therapy is sport, along with sufficient sleep. The first point is easier for me, as I have always liked to move around. Now it has become an almost vital necessity to cope with the pain. As for sleep, it is more difficult because it is precisely these pains and spasms that wake me up several times a night and prevent me from sleeping soundly.

What helps me find sleep is the massage mentioned above, movement and changing position regularly, trying as far as possible to lock my legs so that they do not wobble too much and keep me awake. And then there's relaxation, meditation - in short, as with everything else, managing and controlling my mind.

The mind is not everything, but it is a great support all the same. There are certain symptoms of paraplegia that I have not been able to manage in this way. These include, for example, the frostbite I get every year on my feet due to less efficient blood circulation in my lower body. My legs are constantly cold, and when it is 10 degrees Celsius and below, my feet, which cannot warm up by themselves, get frostbite. The toes turn black, then blister and wound because of the necrotic skin underneath. After two to three months, this subsides, only to start again in another place. In the early stages of frostbite, the foot often swells, and I have already been hospitalized with sepsis and the risk of amputation as a result.

Despite the best socks and shoes, my feet cannot warm themselves in the cold season. Heat must come from outside, but when you cannot feel your skin, there is a high risk of burning. Once again, something very complicated to manage. One solution is to migrate to warmer regions, but how can I

reconcile this with my professional activities? The question has not yet been resolved.

The skin on my legs and feet has become much more delicate and the risk of bedsores, for me as for all other wheelchair users, is very real.

Sometimes I envy those wheelchair athletes who, in summer, play their favorite sport with their skin exposed to the air, without bedsores or scars. For me, disability has left its mark and I can never afford to walk around with my legs uncovered, because as soon as I take off my compression stockings, my feet, ankles, and calves start to swell. What is more, the wind on the skin of my thighs causes electric shock-type pain, which is why I always protect them with a tight-fitting garment that prevents the movement of the fabric on the skin, also a source of pain.

I can already see the good Samaritans coming to suggest this or that therapy or medication. Do not worry, I have tried almost everything... with no convincing results. I do not need to be rescued, I just accept things as they are and focus my thoughts on what brings me joy.

In the list I have given, there are many other things I could have mentioned, but I did not want to make this article any longer, so I have stuck to what seemed most essential to me. I hope, however, that I have been able to shed some light on the subject, so as not to give false hope to publications in the press that only talk about the catchiest themes but turn a blind eye to reality.

Advances in medicine and science bring hope, but all too often they are realized through the eyes of an able-bodied person. We give importance to things that are not priorities for people with disabilities.

Many associations are working hard to enable people with spinal cord injuries to resume their lives, albeit with a few adaptations, but with complete autonomy, and that, in my opinion, is the most important thing.

Despite my severe disability, I have always refused to simply endure my life, and my motto is to make the most of what I have got left. That is how I have been able to achieve prestigious sporting titles, world firsts and performances previously unimaginable for people in my situation.

You see, on the one hand I am admired for my extraordinary performances, but behind this façade there is just a woman who wants to be happy and who fights every day with all the symptoms of her disability to remain worthy and master of her destiny.



*Photo: Tania Emery*