

## “There is nothing I don’t accomplish”

Having a child when you are severely disabled – that’s not done? It is, Joy van der Stel (33) found being severely spastic. And hence Star (6) was born. Indeed did Joy encounter a lot of problems but she thinks that there is nothing keeping you from living the way you want. “There are many disabled people who want to do what I am doing. The only thing is, they don’t dare to.”

Text: Anouk Horsthuis

Translation: Katharina Versluis-Probst

Photography: Eline Hensen



When Joy van der Stel was born, the doctors advised the parents to wait with the birth announcement. ‘She won’t make it through the night,’ they prognosticated. However, the severely spastic Joy turned out to be a fighter. In contradiction to all expectations she managed to build up her own life. She is in a steady relationship, has her own house and even set up her own company.

‘When I was twelve years old I got hold of a report which stated that, had I been born in the local hospital just down the road I would probably not have ended up disabled. Back then I was devastated. Now I see it differently. If someone now offered me a pill that would cure me instantly I would say: Keep it. My disability is part of me and I have learnt to deal with it. It no longer is a restriction to me. I would even go as far as saying that it is a plus in many occasions. The way my life is, the way I can enjoy my life and my family is all thanks to my disability. I know for sure that if I was able to fly and run that I would be just as stressed as all the other people with their busy jobs, two cars in front of

the house and their loaded agendas. And I assume very much that this would not have made me happier than I am now.’

### An independent life was out of the question

‘I was eight years old when I moved to a special living group in a rehabilitation center and was told by my group mates that this was my life from now on. That’s where everything was supposed to happen. School, eating, sleeping. No way, I decided. I want my own space in this world just like everybody else. That I was able to accomplish this is thanks to my parents, who never ever said that something is impossible, and thanks to my perseverance. Definitely not thanks to the rehabilitation center. The rehabilitation world only concentrates on the things you can’t do and not on the things you can. However, I wanted to hear exactly about those things I could do. More importantly, how I could learn those things. The doctors said: “Joy is nothing, can’t do anything and will never be able to

do anything. She will need care twenty-four hours a day, never get a job and never lead an independent life.” My father did not leave it at that. He was stubborn and let me do everything by myself. That was pretty tough but it was my rescue. If he had not done that I would probably linger in my wheelchair now staring out the window.



I have a great ability to find solutions for problems. There is nothing I don't accomplish. This is my basic approach. That does not mean that I never think "oh no" or that I don't see myself confronting a seemingly unsolvable problem. I just never give up. I keep looking until I find a solution. I have unconditional trust in finding one. This is why I do not accept that there are some things that I apparently cannot do. Live independently, an own company, a relationship and children. It all belongs to life and therefore also to my life.



A week after I had met John he asked me whether my condition was progressive. I told him that my condition was neither worsening nor getting better from a medical point of view, which was more or less reassuring for him. However, it took him quite a while to trust this positive attitude of mine. Understandable, if you are not used to it, it is pretty scary. A relationship with a disabled woman, that is not possible? Let alone having a child with a disabled woman. Of course John was not the only one thinking this way. Even other fellow disabled think that way. They think it is scary. Because there are no good devices and because they do not know what to expect. And therefore they do not get started with it. I find this to be fascinating. Apparently people rather stay stuck in a miserable situation instead of fighting themselves out of it. Of course there are many other disabled people who would like to do what I am doing. The only thing is: they do not dare to.

## Launching of a collection of furniture for babies

'What were the problems I was confronted with? Many. For example the time when I went into town with a friend to shop for furniture for the baby room. First, there was the disappointment of not finding any nice pieces under which I could ride with my wheelchair. Then the disappointment that not even my wheelchair manufacturer could help me. There was one baby bed, would you believe it, on legs but it looked like a rabbit cage. When I learnt that the doors apparently opened to the outside which made the thing completely useless and my wheelchair manufacturer said that I would need to get a help at home for twenty-four hours a day to take care of my child, something snapped. Tears in my eyes. I was able to get five thousand Euros grant for a help but no furniture. I was pregnant six months when John said "Then we will do it ourselves. Your wish is my command."

Just right before Star's birth all the furniture was ready. Since then we sell our collection via internet and have made a virtue of necessity.

For the rest, my pregnancy luckily went smoothly. I know my body and know what it can handle. On top of that I have learnt not to treat myself negatively and therefore never felt guilty when I went for a nap. I would never say to myself: don't be so stupid, you have to do this and you have to do that... Frankly, I do not have to do anything. I do not push myself. I do not have to be able to do everything; you can ask others for help.'

## Accustomed to each other quickly

'Naturally we had to get used to having a child. Just like all fresh parents. Due to the caesarian section I could not move. We did not have help.

And Star turned out to be a night bird. After five weeks John was exhausted. "You have to get out of your bed NOW because I won't survive this otherwise," he said in the middle of the night. Suddenly, you are forced into finding a solution. I knew this pattern from former times and therefore set myself to think. How are we going to do this? We changed all buttons and such on Star's clothing with Velcro. We had a serious agreement over what I was able to do with Star and what not. For example, I could not let her play on the floor when I was alone with her because I could not pick her up. However, I was able to feed her and dress her.

Star and I got accustomed to each other quickly. Whether I held her up upside-down or picked her up by grabbing her clothes, Star thought it was all completely normal. As soon as I had things figured out I didn't even need to support her head anymore. Thinking back now I think it all went so smoothly because I made a game out of everything. When she would slide from my lap I put a box on my footrest and encouraged her to climb back up again. Also getting dressed didn't have to be done within ten minutes. I allowed her to explore all the corners of the cupboard and boy, how much she loved that!'

## Hurtful reactions

'When Star was about two or three years old she began to notice that people on the street would look at me in a different way. And just like her father she reacted by looking back with an angry face.



One day I explained to her that people look because my body moves differently from theirs. And everything that is different attracts attention. It's a reflex; they do not do this on purpose. You are better off if you smile at them and do not get angry. Of course I know that this is better but sometimes it is really difficult for me too. For instance the first time I went outside with Star and somebody asked: "Is that your child?" I was still full of hormones and was incredibly hurt. But it also helped me to see things clearly again. Oh yes, that is the way the world sees me. The biggest insult I received a couple of months later in a shopping mall while standing in line for a coffee. An elderly couple stood behind me and looked into the Maxi Cosi which was fixed on my wheelchair. I will never forget their comment. "What a beautiful child. It is probably not hers. "

Luckily we know better. We are a great threesome. Of course there are things I cannot do but I always ensure that there is someone else who can do those things with Star. The disability is mine after all and I do not want to limit her with it. We therefore never say: "You know that mom cannot do this?" What is important is that our home is safe and fun. And that is the case.'



*Joy van der Stel (33) is married to John and mother of Star (6). She is a counselor, coach and trainer and leads her own company: [empowermij.com](http://empowermij.com). She wrote a book, "The Power of my Disability" (probably published in September 2009) about her life and the choices she made.*

*More info: [www.empowermij.com](http://www.empowermij.com) and [www.kubinc.nl](http://www.kubinc.nl) (wheelchair friendly furniture)*