

Paralyzed Kati Lepistö: "ONE HAS TO DARE TO LIVE"

Car turns into a driveway of a house in Mikkeli. The daughter of the family has visited a hairdresser and a make-up artist for the shoot. She has chosen her outfit as carefully as during her modeling years. Although she has been paralyzed for 13 years there are still things that you don't belittle.

When Kati Lepistö, 34, got sick in her twenties to Locked-in syndrome the lives of the whole family came into a stop. After one work trip Kati started to feel bad and powerless until even her speech became unclear. Little by little after her own words she felt as sinking under water where she heard and saw everything but couldn't do anything herself anymore. Infarct in the brainstem had destroyed areas in the brain that give orders to muscles.

In the Locked-in syndrome brains remain in the same condition. One still thinks, remembers, reasons and can "speak" languages just like before. Kati was imprisoned by her own body. Locked in inside herself. Eyes were the only thing that moved. After the rehabilitation she was able to move little her head and sit in the wheelchair.

When it became clear that her condition wouldn't change life was nothing but chaos and crying. All Kati wanted to do was to die. What joy could there be anymore left for a young and beautiful girl speechless in a wheelchair? Why just her had become sick with one of the world's rarest sicknesses? After the months of horror and confusion one thing became clear to Kati. She doesn't survive without goals. One just has to go on and in no way to be afraid.

At first Kati had to learn a new way to communicate. She practiced to use a letter board with what she formed words by looking at letters one by one with her eyes. In a while the places of the letters were corroded into her mind so that the board was no longer needed. Kati showed the letters from air with her eyes from where they were picked up by mother or her personal assistant.

Fairly soon to help came also computer. To forehead between eyebrows was placed a small sticker with what Kati picked up letters one by one. A window to world to friends had opened.

Family started to travel to far away warm countries because warm weather did good to Kati's muscles. A wheelchair couldn't be an obstacle. Dad Risto points out that he would have never seen world so much if there had not been Kati's sickness. Then came out the book *In a Blink of an Eye* where she tells about her life as model in Los Angeles and about the sickness with the help of her co-writer Leeni Peltonen. Now a new challenge has arrived to Kati's life. A man from the island of Aruba from the other side of the world.

Are you mad!

How on earth from Aruba a small island on the northern coast of Venezuela? Kati laughs. B O O K she starts to spell with her eyes. Mother follows the gaze of her daughter and guesses the rest.

In 2006 in Kati's book publishing party had been ordered Jani Wickholm to sing who had to cancel his appearance .Who could replace him .Kati had met on the Internet singer who lived in Aruba but was just touring in Holland who came to rescue. Marcos came ,performed and left .

Because that whole beginning of the year had been awful hustle around the book they were dreaming of warm beach life. First they were thinking of familiar California but Kati suggested Aruba where they ended up going for two weeks .

Aruba that belonged to Holland is 30 kilometers long and 20 wide where they speak Papiamentu,Dutch ,Spanish and English .When Marjatta ,Kati and assistant arrived to the island Kati's friend Marcos was also there and he was the tour guide to the women .

Couple nights before flying back to Finland it happened .Marcos 'friend and colleague Toni Marchell noticed Kati and wondered how come such a young woman was in a wheelchair . The man started strangely appearing every night to the company of Finnish women .On the day of departure he begged for women to stay a week longer wanting to even pay for the extra week but dad Risto was already waiting for women to come home .

At the airport Toni put his golden necklace around Kati's neck and said he would come to pick it up from Finland . Two impulsive but very different persons had met each other .

Feelings in homeland were mixed .Kati was in love and they were chatting daily with Toni who asked Kati to come back tears in his eyes .Dad was worried .Who was this man ? What is he aiming for ? Can his affection be real towards a paralyzed woman ? Is the man just playing with his daughter and then breaks her heart ?

Despite dad's worries the Internet chatting just got more intense. Toni suggested more serious relationship . He wanted to go steady with Kati .

-On one day I wrote to him : "This is your lucky day Mr.Marchell "Let's try going steady and see what happens Kati tells .

During her daughter's sickness Marjatta Lepistö has realized that you should live your life fullest.- Nothing in this life is sure .Relationships between healthy people don't last always either .Isn't one happy day better than one completely lonely life? Surely I have thought what happens to Kati if the relationship comes to an end. I have said to Kati that of course Toni could handle it but could you .

Kati's closest people were horrified: Are you mad! You can't let Kati go back there . You know nothing about this man .-But Kati is a sane person .I can't stop a grown up person Marjatta points out .

Harder than I thought

Kati left to Aruba with her assistant .Mother traveled later to the island to see how the lovers were doing . – Toni admit to me that he didn't know that the everyday life would be so difficult . There are easy moments only when Kati is reading on terrace or she is being pushed in a wheelchair . In all other everyday's things you have to be there 100 % all of the time . Even at night you can't completely rest because Kati has to be turned .

After 6 week trial period the couple decided anyway to go ahead with the relationship . Toni left to Finland with Lepistö to introduce himself to dad .

Former professional cyclist Toni Marchell isn't your regular guy. 51-year-old Dutch Indonesian has experienced all kind of things. Also bad ones. He is lively, uninhibited, very forth speaking joker. Responsible, in some way very conservative and always talking. Toni entertains tourists by singing evergreens in restaurants, keeps an art gallery and trains parrots who perform every night to tourists. He rescues abandoned dogs and cats. Once he even brought hurt little bird home. When he lived in Germany he had a lizard in his garden. Now he has many but wild ones.

Kati has also English letter board from where her local assistant Michella learned in 3 weeks to find the letters from the air. Toni still has in his pocket little soft board to remind him of the places of the letters. Toni claims to understand Kati even without some board. One unbeatable system the couple has though. I write e-mail to Toni every day. When you fight you often say things that you don't really mean so when we have fought I go to computer. I have time to calm myself, gather my thoughts and really express what I think and feel.

In December Kati's parents flew to Aruba and Kati and Toni got engaged. On Kati's finger is a big diamond ring that has on its side small looking diamond to Kati.

Learning to live in a relationship

Nowadays Kati mainly lives in Aruba but also still visits Finland months at a time. She tells how the take off from home does extremely good. She feels more independent and grown up than before.

Risto Lepistö still isn't sure. He relaxed a little when he saw a photo of Toni feeding Kati on beach. I guess the man wants to take care of Kati then. I guess he is serious.

Was Kati afraid to move in with Toni. To throw herself into a new and complicated relationship? - I didn't have time to be afraid because the new situation acquired all my time and attention. Once mother panicked why I have not written e-mails for couple of days and I just pointed out that it's far more important for me to get this relationship working than to write to Mikkeli how I am doing Kati tells.

What concerned Marjatta Lepistö the most was how Toni would handle and accept everything.

-We are in touch with Kati daily with computer and web cam Marjatta tells. If I have not heard from Kati for a day I start to worry. Once we were chatting with Kati and I told to her that I'm alone. Kati replied that she too. I got pretty worried because Kati can just lose her balance in the wheelchair. Luckily Toni came home right away. He had just stopped by a market. I do trust to Toni anyway. If there were problems he would call an assistant present. Luckily he doesn't use alcohol. Alcohol just would not fit into that relationship because you just can't lose control with Kati even for a minute.

Kati admits that a two year relationship also includes many fights. - Last fall Kati told to me that she had already twice almost packed her things and left. When we shipped her standing support to Aruba I said to Kati that don't get rid of that box. You might need it some day.

When Kati was still healthy she sometimes when upset banged the doors when going upstairs so that the saw dust fell from the ceiling.

-We are both very stubborn and we get into fights from the smallest thing . When making up I as a Finnish apologize and he gives wet kisses Kati tells .

In addition of my disability also big cultural differences put a strain on our relationship . For example In Indonesia grown up people are not allowed to cry and show sad feelings what I do vey much . Then there are differences in characters not to mention age difference so there are plenty of obstacles to win. If I could speak we probably wouldn't be together anymore Kati laughs .

Rather a lion than a lamb

Before anything Toni is Kati's partner and not an assistant although he has capabilities to face many kind of disabilities. He has given judo- lessons to disturbed children and taken care of elderly . Nothing human is strange or uncomfortable to him . Kati has had boyfriends also before when paralyzed but none of them were ready to take that kind of responsibility what Toni has.

Also in Aruba Kati has to have two assistants because help is needed in everything . One can not tire one assistant too much . – When Kati is in Finland my time goes completely with her. Probably it's my luck so I don't have time to worry about anything . When I'm alone fears and worries sneak inside my head .If I lived all alone I might become bitter Marjatta Lepistö admits .

Often families with disabled members are afraid to travel .Family Lepistö have visited Caribbean , Mexico, USA, Asia (even 3 times in Bali) and in many European countries .Usually travels with a wheelchair go just fine . Only once Marjatta lost her nerves with airport personnel when seats that had been promised before hand a flight to Verona seemed impossible to get .

Kati's Arubian assistant Michella has come to Mikkeli with Kati from where they return back to Aruba in August . Then starts again the normal everyday life ; grocery shopping , relaxing muscles in the warm water ,cooking . But before anything comes laughter .In the morning when Michella arrives women first talk for a LONG time and laugh at their own stories .

-Many people think that because Kati can not move nor talk she just cant be sane. Some people think Toni is some kind of hero for being with a disabled woman but they don't know what he gets in return says Michella

Has Kati been afraid at all ?

-I can not even think what I would be afraid of. Even as healthy I went alone in LA in pretty dangerous modeling world and was not afraid one bit. One must dare to live. I have the same principle towards life as Toni : I rather live for a year as a lion than 10 as a lamb.

