

Patient story of Joppe Jansen (age 47)

After New Year's Eve my throat started bothering me. I had difficulty swallowing, it felt like flu, I had a fever. I thought I just had a regular winter flu. My GP gave me antibiotics for a throat infection, and then I did what everyone does: I crawled into bed to ride it out. But just a few hours later breathing became difficult and my lungs would tighten as soon as I sat up. The ambulance paramedics suspected an allergic reaction to antibiotics and took me to the hospital straight away.

We got there pretty quickly. I was given oxygen, two hours later I was in the ICU, and the first signs of delirium began almost immediately. I was totally convinced that my children were sleeping next to my bed, I saw doctors and nurses at an après ski party in the ward, the army was training outside the door of my room, I was in photo shoots, I saw paintings moving in the hallway. It was bizarre. You are so unwell that everything seems real, that's what's crazy about the whole situation. It was only after my wife told me that none of those things had happened that I realised I must have imagined them. As soon as you realise that, what seems like an unstoppable fight begins in your head between what is real and what is imagined.

All in all, the delirium lasted three days without the doctors or nurses noticing it. Isn't it strange, the way things can happen with a quiet delirium? A patient can lie in bed and be hallucinating, without a doctor or nurse noticing it. I stayed in hospital for a total of four weeks, with what turned out to be sepsis. I was balancing on the edge of death for two weeks, and every morning they wondered if I would wake up again. I also had the risk of low blood pressure, which could result in organ failure. The infection in my throat extended to my neck and was threatening to spread to my lungs and heart, so my neck needed to be surgically opened and cleaned. In the end, the last possible antibiotic cocktail worked, and I started to recover.

We are now a year and a half further down the line, but I am still having to deal with the effects. The physical rehabilitation lasted six weeks, but that is nothing compared with the time it takes to recover psychologically.



DELTASCAN[®] BRAIN STATE MONITOR

Bedside EEG for medical decision support acute encephalopathy ● delirium

The mental consequences of such a dramatic experience are truly unbelievable. Small things that never used to bother me can now cause triggers that affect me intensely after the delirium. The five of us sitting at the table, everyone talking and gesticulating at the same time, that could irritate me no end. Or the sound of the TV, things like that. It sounded really loud to me, even though it was set at a fairly low volume. And I would lash out at the children. I had no filter. I could only think unidimensionally, I could no longer associate or think things through. If I went to the supermarket for bread, it wouldn't occur to me to check whether we needed anything else. Just going to bed was not a good experience because it reminded me of all the lonely nights in hospital, and I had difficulty dealing with emotions of the family which led me to start crying at the drop of a hat, and that obviously sometimes annoyed my wife and children.

Three weeks after being discharged from the hospital, things got to a point where my wife suggested I get help my psychological state of mind and aid my recovery. That felt like a revelation. I so much wanted to be my old self again: the father I want to be for my children, the partner I want to be for my wife. But I couldn't do that alone and definitely not without help. Via Google I came into contact with a coach who had a lot of experience with patients that had stayed in ICU, some of whom had experienced delirium. One of the first things I learned from her was that there is no longer an 'old me' and that I should take a discovery journey to find the 'new me'. You have to get to know yourself again, discover what you are dealing well with and what you still have difficulty with. You also learn that for some things there is a physical explanation. For example, your nervous system was in a state of hyperactivity in order to survive, and it takes a long time for it to calm down again. This is important to know as a patient, as it allows you to give things some space.

I also learned from my coach to solve things on my own without intervention when a situation became too much for me. You can simply walk into another room and say you'll be right back. It is important to explain why you do certain things, so that it doesn't feel as if you're running away from your family. She taught me to meditate, which helped a lot. I had to learn to listen to myself, pick up on signals, and take a step back as soon I notice that I'm exceeding a certain limit. It has not been easy, but I'm doing better all the time. For a long time, I was also bothered by flashbacks to that awful time in the hospital. I have also had to learn to accept that I have them and that I have to live with them. The entire process after a delirium is in fact a major lifestyle change. I am utterly convinced that I wouldn't have been able to get over it psychologically on my own, without help.

“All in all, the delirium lasted three days without the doctors or nurses noticing any of it. Isn't it strange, the way things can happen with a quiet delirium?”

Joppe Jansen
Patient