

My-corona adventure

In diary style, I will describe how I experienced the corona virus as a Duchenne patient.

Friday 03-06-2020

I feel like having a cold, I have to sneeze, and I have got a headache.

I use some nose spray, trying to keep my nose open as much as possible.

I'm still not weak or anything like that, so I did not directly consider Corona.

Sunday 03-08-2020

My temperature has increased to 37.5 Celsius. Since I don't often have a fever, I start to worry about having Corona, so we called the doctor on duty. The doctor came and said it is a tracheitis. He did not immediately consider Corona, because neither I have been to a risk area, nor have had contact with someone with Corona. And, my lungs sound clear. The doctor said that if the fever wasn't over by Tuesday, I should take antibiotics.

Sunday night was a bad night. I started coughing, and was shorter of breath. We called the doctor, and he starts immediately with antibiotics. Still, he doesn't worry about me having Corona.

Monday 03-09-2020

I started a wide spectrum treatment of antibiotics.

Tuesday 03-10-2020

I feel weaker. Breathing remains poor. I don't know how to lie or sleep. Four hours of sleep is already a lot. This continues until Wednesday night.

We called the doctor immediately on Thursday. He was able to come over in the afternoon. When the doctor arrived, he notices that I'm totally exhausted, having a high heart rate and breathing heavily, and some noise in my left lung. He decided to call the emergency room and I prepared myself to go there.

Thursday 02-12-2020, 14 pm – arrived at first aid

Arriving at the emergency room, they do directly know where to put me, and we could hear in the background: 'but that's a Duchenne patient'. I couldn't hear the remaining conversation. We had to wait in the waiting room (in my opinion, they did not correctly handle this), but soon I was taken into triage and I immediately got oxygen (saturation was beneath 88). They immediately brought me to a room after measuring the parameters.

Furthermore, I got an immediate infusion of antibiotics cocktail, they took a blood sample, and came to take a picture of the lungs. My heart rate was around 160, and they said that I arrived to the emergency room in a kind of shock. It was not a good idea to come over by car. It would have been better if the doctor had provided an ambulance. Anyway, we are now in the emergency room, the parameters are monitored and I feel much better with the 3 litres of oxygen that I get.

At the emergency room, the doctor was completely covered and they all wore masks and goggles. The fear about having Corona is starting to get me. And of course, a little later they tell me that they are going to do a flu and Corona test. With a long cotton swab they go very deep into my nose, until I get tears in my eyes. The Corona test was painful. But it was necessary. From the room I was at that moment, they took me to the intensive care, behind a curtain. Including all the wires to follow the parameters. They went to take another echo and cardiogram of my heart, because I still have some pains in my heart since I got antibiotics on the drip. Just to be sure.

And then, at 20 pm, they came up to say I was tested positive for Corona, so “We're going to take you into isolation”. At that moment, it was up to my mom to decide what she was going to do. Whether staying with me in the isolation room in a fixed place, or going home and not being able to see or help me for 14 days. If she goes home, coming back here in the hospital wouldn't be an option, but sending someone else so that she could go home was also not an option. This was a hard decision. On the one hand, she wants to be with me. Caring for someone with a muscle disease is something completely different then caring for someone with Corona. On the other hand, she wanted to go home. This because mom smokes, and it may be very difficult for her, but also for Dana, and dad of course.

Mom decided to stay with me and use nicotine patches. The nurses promise mom to help her with this. And so, I ended up with mom on the department of pneumology, where they have two rooms adapted to go into isolation.

It is all so intense now. A white paper sheet, is put over me and we leave to the isolation room. Two nurses and the head nurse waited for me in the isolation room. A nurse installs me and then they leave the room quickly. After this, we receive a phone call and the head nurse explains what is going to happen.

APPARENTLY, I WAS THE FIRST CORONA PATIENT IN GASTHUISBERG

Whenever a nurse or doctor enters now, they are completely covered and they carry a police helmet (as one used in demonstrations). Mom sleeps on a sofa-bed.

Friday 03-13-2020

I feel pretty good, but am still dizzy and strange in my head, and there's pressure on my lungs. Eating is not going well, nothing tastes (already had this before I came here). I tell myself I have to fight against the virus and that includes eating. From that moment on, I started eating again. I still have a fever, so I get some extra Dafalgan. They stopped the other medications (except calcort and pantomed for my stomach), because my blood pressure was quite low, and my Lisinopril contains a substance that could strengthen the flu symptoms.

Low blood pressure may also result in dehydration. Therefore, I get a drip with extra fluids too. The physio comes along in the afternoon and gets me to practice with the blue balloon (airstacking). Shortly after the session, I suddenly feel less short of breath and I feel normal again. I do not even feel sick anymore and the parameters are fine.

Saturday 03-14-2020

The day starts a bit worse: my temperature has gone up and I feel weak in my head. I ask the physiotherapist to come over earlier. The physio comes at 14h instead of 16h. We repeat a few sessions airstacking and I feel much better. We ask the nurse to bring something to keep us busy during the day. And mom asks for her medication and some clothes. The thought that you have Corona and have to stay for a while doesn't to mind when you are suddenly brought to the emergency room. They could bring a bag to the hospital. The books and crossword puzzles they brought weren't helping, because I wasn't able to focus.

Sunday 03-15-2020

Nothing special, I am doing fine. The oxygen is reduced a little.

Monday 03-16-2020

Monday begins very well, the fever is gone, saturation is much better, and they lowered the oxygen supply.

Monday afternoon I got my food just at 13:30. Shortly thereafter, we expect the physiotherapist, but suddenly we receive a phone call. I hear them saying something about going to the intensive care and my mom not being able to stay. My heart starts beating harder, and I immediately call my doctor. I explain to him that I feel very good, and what they are planning. The doctor wants me to go home. But unfortunately, the head nurse is not really tolerant and decides to come in my room. This leads to a discussion that my mom wasn't able to stay there. And they refused to understand that being home would be better for me and for my mom. Because in the recent days, mom always took the parameters, if we needed something for the bedpan (as needed with special packaging, etc.) or even water or tissues etc., then mom had to note this and had to call someone and if I wanted to sit up straight, my mom helped. So, mom wanted to explain to him that they would have to change clothes for doing little things. At that moment, the physiotherapist enters (for doing the airstacking) and I said 'it is not the moment' and she answers, " Bert, it's now or not anymore at all. And she was right of course. But it felt like she had come to persuade me to listen to the head nurse and just to go along. The head nurse said, still very cru 'Bert, either you come over now, and you are getting good care and you receive the rest of the antibiotics, or you go home and then you'll probably die'. So, yes of course I had no choice. It was a hard moment. But I also could understand the difficult situation for them and the stress it was bringing them.

Arriving, "very angry" at the intensive care (I thought, I'm healthy now and they make me going to the intensive care). But apparently, they were planning to put all the Corona patients, at that time three patients in Gasthuisberg, together. There, they measured all the parameters. My saturation was again 85, this means: back to the oxygen. At that time, I felt distressed and I could imagine staying here until Thursday. Luckily, there was a very kind nurse who understood our situation. But unfortunately, he wasn't able to do something about it. He did send an email to his boss about the situation.

I made a phone call with several people that day and felt really sad about the drastically changed situation. I have therefore called to Goedele from the NMRC in Gasthuisberg, they were not even aware of me being in the hospital. This could be improved in Gasthuisberg. Fortunately, then night came quickly, although it was a terrible night.

Tuesday 03-17-2020

Another kind nurse comes to wake me up and measure all the parameters, gave my medication and prepare my breakfast. Then he washed me and put me straight in my bed. Then I had to call for having to go to the toilet. Half an hour waiting, and then finally, I could go to the toilet in the pan. Not really comfortable, but it went well. Shortly thereafter, I again felt as if I had to go to the toilet and so they had to come back.

During the day, I asked to put me a bit higher in my bed (and I heard for the first time 'you should not call so often, there are other patients too'. I thought; that's where we warned them for and that's the reason my mom should have come along. But if I needed anything, I called and they came. So, I cannot complain. But it was a lot different compared to my mom, who knows me and the easiest approaches and can take time for this, so the nurses would have more time for other urgent things.

At lunch, which was prepared by the nurse, I took off my oxygen, because that's easier during eating. After that, I stayed without oxygen and it actually went pretty well.

Half an hour later the doctor arrived, which had been in contact with my doctor. He saw I no longer needed oxygen. He looked at me and considered of letting me home because I was looking good without oxygen. Hereafter, everything was prepared to get me home.

Tuesday afternoon – back home!

I am glad being back home. But still, I need to be in quarantine for another 2 weeks. I am separated from dad because he shows some symptoms of Corona. The rest of the family has not been tested, they just assumed that they would have tested positive. So even Dana and dad need to remain in our house, as well as my brother and his girlfriend. Fortunately, I have a studio at home, so it is easy to keep me in quarantine.

I'm doing very well, although I'm still tiring quickly and my muscles must strengthen slowly. Sometimes my head feels foggy.

We are now a few days later: it is starting to go very well and I can even do some work again on the computer. I often have a dry mouth, and there are moments where I struggle to get my breathing under control. Some things I liked, do not taste as good as before. For example, I do not really like coffee anymore. And pepper tastes suddenly much stronger. Apparently, these are also symptoms of Corona. I have found my new love, however, tea. I enjoy it.

This was the story of Bert Gooris from Leuven, 29 years (on 03-28). If you have any questions about my adventure, shoot, and I will do my best to answer it. We are in this fight together.