

Edgar Stene Prize Competition 2017

Runner-Up: Nanna Hanquist Johnsen, Denmark



“I am 24 years old and live in Copenhagen where I study physical education and English at the University of Copenhagen. My ambition is to become a senior high school teacher.

In my leisure time, I am just like other young people. I love to hang out, have a good laugh and eat cake with my friends. To exercise, run in the sun or swim some lanes. To dance all night at a great party – and to eat pizza and play Yatzy with my boyfriend the day after. I am rather adventurous and travel as often as the grant from the State Education Fund allows me to. These days some of my spare time is also used at hospitals, taking blood tests etc. These are things I do not love, but, well, it needs to be done. Tough luck.

I read about the Edgar Stene Prize on Facebook and immediately I thought it was a good way for me to work with my feelings and thoughts. My own words gave me the time to think and a belief that everything will be all right.”

Early diagnosis and access to treatment – in the ideal and the real world

Me and my diagnosis

“There’s certainly no doubt that you have rheumatoid arthritis”. Silence. The words hit me hard. A hard slap to the face. A bludgeoning blow landing right on the spot where it causes the most pain. I look uncomprehendingly at the consultant. I try to say something, but the sound has completely disappeared from my lips.

This is a normal Friday in my life. I’ve been referred by my GP with suspected reactive arthritis – and I just thought this consultation at the hospital would be 10 minutes and give the reassuring information that I would probably get better. My joints, which had been swollen and painful for the past six months, would soon be better. Back to normal. That’s exactly what the consultant would say. Then I’d cycle to a university lecture. Continue my normal life. In my world. A normal Friday. Twenty-four-years-old, fit and healthy, studying sport, a non-smoker. Why would disease affect someone like me?

I sit in silence. Uncomprehending. The consultant starts his steady, patient explanation of my diagnosis, but I’m not listening. I’m still knocked out by the shock and am trying to focus. The room is made hazy by the tears which are slowly filling my eyes. I dry away the tears in frustration. Breathe. The consultant halts his

torrent of speech and gives me a determined look of understanding: “You mustn’t cry, Nanna. We’re going to get you fixed.”

This is how the story about me and my gout started. A diagnosis which, following a three-month investigation, proved to be mixed connective tissue disease. A disease which I had never heard of before, but whose symptoms were a perfect match with mine. Swollen fingers. Excessive tiredness. Body pains. These have been the most difficult months of my, relatively, short life so far. Hospital appointments several times a week to clarify blood tests, urine tests, lung function test, X-rays, an ultrasound of my heart and many more things. A diagnosis was what they were after. Everything was examined in depth. More blood tests. Another trip to the consultant. While the doctors endeavoured to arrive at the right diagnosis and treatment, I struggled with acceptance and self-confidence.

My experience of my diagnosis is not far from the ideal world. This is mainly because of my previous association with the rheumatology department. Right from the first day, I was dealt with by unbelievably able and ambitious personnel who hoped things would go well for us patients. I’m unbelievably grateful and humble, given the huge effort the health team make.

When I didn’t understand the doctor’s Latin words and jargon concerning the preparations, I was always able to pop in to see the nurse and have a chat, a hug – or a shot of adrenocortical hormone for that matter. Both things gave me a feeling of improvement.

In the real world, diseases can play tricks on even the most capable doctor. Irrespective of how hard you work, you have to accept that no two people are the same, and all diagnoses are different. And I was no exception. However, I do wish that I hadn’t been confronted with three different diagnoses on the way to establishing the final one of mixed connective tissue disease. It would have saved me many worries and angry outbursts – and numerous hours of research on “netdoktor”.

When a person is faced with a crisis, we go through various phases of grief, anger, denial, working through and acceptance. I went through this phase three times. Each time I was equally distraught about what the new diagnosis would involve for me and my future. For my world. After all the consultants had examined me and the final diagnosis was established, I was in no doubt that it was the right diagnosis. Believe it or not, it was a huge relief.

In the ideal world, the diagnosis is established the first time you go to the hospital so you can work your way through the process as quickly as possible – and come out the other side stronger and process the information. But that’s Utopia.

However, aside from this wishful thinking, my diagnosis is incredibly close to what you could wish for in the ideal world. It was a secure and pleasant process during which I was always able to contact the rheumatology department if I had any questions, or needed guidance and information, injections and pills, cream and tissues.

I've just started my medicine. I'll be glad if it works. I've got over the blow I received on that Friday morning at Frederiksberg Hospital. I want to do everything I can to get on top of it. And, fortunately, I'm surrounded by the best network of friends and family in the world who will support me through the process.

I thought my diagnosis was the end of my world. But I became wiser and have learned an awful lot during this process. A diagnosis can feel like a slap in the face; the world's worst knockout. But I've got up again and, this time, my self-defence is up. A small number of people with my diagnosis do feel that the disease will disappear. That's not what I think. In any case, I have no intention of giving up without a fight.