

Edgar Stene Prize 2015

“Taking control of my life – working together with health professionals to achieving my personal goals”

Winning essay by Charlotte Secher Jensen, Denmark

Living in the moment

I still remember that day. The day I was diagnosed with rheumatoid arthritis. My thoughts were all over the place. They whizzed round and round in circles, in utter confusion... Why? What was it all about? And what now? That night – the night after that day – is what I remember the best. How I wept silently into my pillow until you could have wrung it out. How I crept into the kitchen in the dark so as not to wake the family, and turned the thermostat on the radiator up full. I remember the reassuring, monotone clicking of the radiator and the warmth, the meditative shushing noise it made, like the sea, calming, giving me a kind of artificial comfort.

I sat myself down awkwardly on the hard kitchen floor and leant into the radiator's unfeeling arms, which gave me a warm, weak hug. I sat there in the dark heavy hearted. I felt the burn on my back where, I hoped, I would one day have my angel's wings in my fantasy world. The burning pain gave me a few seconds' peace from the sharp stabbing I felt in all my limbs.

My tears dried up. Something happened. My thoughts folded their wings together; I took a deep breath and got determinedly to my feet. A battle was raging in my mind between light and dark. And the light won! I intended to live in the moment and in the future. This was my life. My decisions. But I quickly realised that I needed something to lean on. I had a long journey ahead of me.

I soon learnt, the hard way, that there are three different types of hospital visit. Those where I leave the place no wiser than before. A waste of time, waste of money and waste of the present moment. Then there are the visits where I leave in tears – either because I have not been seen or listened to, or because I have had to behave too much like a chronically ill patient.

Perhaps it was one of those visits where I had to have examinations and blood tests that I simply did not have the strength to endure. That felt like a violation of my exhausted body and frayed mind. With a doctor or a harassed nurse who, I felt, held my future life in their hands. He or she would barely look at me, looking down instead at the notes that they should have read – or at least skimmed through – before I walked in the door. Tired eyes and non-committal comments, “Your blood tests look fine. So you should be alright.” I feel as if I am just a number. Number 13 in the never-ending queue of patients. They leave – I leave – with hopes dashed.

And then there is the last kind. The best kind. My favourite visits. Those where the doctor or the nurse asks, “How are you?” and I answer, “I am very well.” They nod, lean back attentively and say, “And how are you really?” I am aware of the person beneath the white coat, the warmth of their eyes, that they want me to be well, to have a good life, in spite of the excruciating pain and powerlessness. They have read – or at least looked through – my notes. They remember my name. I am not a number.

Those visits are the light at the end of the tunnel... When you are way down in the dumps and the nurse smiles warmly at you and says that everything will be alright. That I can phone any time for a chat about anything at all. That although she doesn't have rheumatism herself, she recognises – because she has seen it all before – the powerlessness, the fear, the helplessness about medication and side effects and all the rest of it that I end up spilling out because it has taken hold so deep within me, and at long last there is someone who knows how to press the right buttons.

I feel the weight lift from my shoulders. Everything loosens up. It's going to be alright. My shoulders relax and I can breathe freely again. She is careful inserting the needle, comforting me all the while. She gives me hope and belief that the present moment is OK, the future will be better, that it is possible to learn to live with rheumatism.

It takes time. Body and mind alike have to get used to the upheaval. And so do family and friends. You are no longer the same. Your body creaks and groans. I sit nervously in the waiting room and look around me. I am surrounded by people young and old. I am sure they all have rheumatism. Some have their loved ones with them. Others sit there alone and wait. In a way it helps, knowing there are others with the same symptoms as me, but at the same time I feel their pain. The uncertainty that we all have about the present and the future. No doubt we all have the same burning desire to make the best of our diagnosis, of our lives and to take control of our illness?

I sigh... Because of what is written in my notes, because I didn't get on with the lady doctor I saw last time, because I don't want her ever to write another word in my notes. I had strength enough and was able that day amidst all my hopelessness, disappointment and unbearable pain, to say no. The nurse and I had a good talk over the telephone as she had promised. She took the call in spite of her heavy workload. I am grateful for that chat and nervous about who I am going to tell my life story to this time. Every time it feels like an exam – a 10-minute exam in which I have to relate as much as possible before my time is up. Not so much as a "Goodbye. See you again in 3 months. Don't forget the blood tests." I pretty well know in advance what it will be like. I feel anxiety weighing heavily on my pounding heart, and my invisible protecting wings cradling me so tightly I can barely breathe.

I catch my breath when my name is called. I look up anxiously and meet a pair of warm eyes. There he stands: the doctor, welcoming, leaning casually against the doorframe in a T-shirt, white coat unbuttoned, jeans and trainers. Still, I am on my guard. I follow him, wearily. Sit down heavily on the chair and try to swallow, but my mouth is dry. I am almost unable to start my story all over again.

The doctor leans forward in his office chair. He leafs through my notes and I feel the hope grow within me. I look at him, surreptitiously, and my warped mind cannot stop thinking that it is not good for a person to have so many little books stuffed into the pocket of a coat. Bad for the back. I meet his friendly eyes with a cautious smile, which only widens when I hear the sentence: "So, how are you?" I hear myself lie – I answer him, "I'm OK."

He rolls his chair towards me – the books knock gently against my knee. He asks again, with a sparkle in his eyes. I feel the relief and realise that I am smiling up into his eyes, even though the tears are trickling slowly down my cheeks. Politely, he hands me a tissue, smiles encouragingly and examines me carefully but firmly, with a comfortable pressure. I relax. He scans my jaw, wipes away the clear gel from my cheek with a practised gesture, and comments, jokingly, that it isn't doing a lot for my hairstyle. I smile. No matter that it is still sticky all down my neck; he is forgiven. He hands me another tissue, so that I can try myself to remove the last traces without completely ruining my hairdo.

While he is talking, explaining, reassuring, he holds my gaze. We are both present in the moment. The tears stop. I hear myself tell the truth. I even manage to recognise that it will not get better. That it is not going to go away. But that it will still be alright. I am OK. He listens, he sees me, he hears what I say. His words give me hope and his interest helps

honest words find their way from my thoughts to my tongue. He carefully examines every joint of my fingers, and his warmth, vitality and charisma flow out to feed my recognition that there is a life with rheumatoid arthritis. Maybe not the life I had dreamed of, but a good, full life.

I leave the hospital with a smile on my face, even managing to spare one or two for the patients in the waiting room. Outside, the sunshine dries the last tears from the corners of my eyes. I take a deep breath, straighten my back, feel my inner strength awaken and walk purposefully over to the car park out into the world.

I am ready to live in the moment and to meet the future. It is possible to travel with rheumatism in life's rucksack, provided you have help to pack it properly. I embrace the present moment and I embrace life!