EDGAR STENE PRIZE 2015 TAKING CONTROL OF MY LIFE: WORKING TOGETHER WITH HEALTH PROFESSIONALS TO ACHIEVE MY PERSONAL GOALS

My name is Maiken Brathe and I come from Elmshorn, near Hamburg in northern Germany. I am 44 years old. I am not married but I have been in a relationship for 20 years.

I have had polyarthritis in all my joints since 1980 when I was 10 years old. I am severely disabled by the disease.

I became aware of the Edgar Stene Prize through the German Rheumatism League’s periodical Mobil.

My first years with rheumatism resembled a science fiction film – it was 1980 and I was 10 years old. I was lost, not only in pain, but also in my life. My parents did not believe me when I could hardly walk in the morning and play in the afternoon. Even a stubborn attack of fever did not help me to be believed – instead it gave me the status of something special. I now counted as an “interesting case” in the countless clinics in which I was passed around from doctor to student, from auditorium to lecture hall.

And when I asked what was happening to me, what examinations were being carried out, whether I was going to die, I never got an answer. I felt as if I had been spirited away by extra-terrestrials who dressed in white coats and masks, strapped me to tables, stuck needles into me both front and back and experimented on me. I couldn’t understand them. They were not from my world.

Three years and two hospitals later I was sent to a rheumatology clinic for children. I was all skin and bone, and unable to walk more than three steps. People in white coats – aliens in my eyes – caused me to panic.

“We have all succeeded in getting our lives and illnesses under our own control”

When I first met my new ward doctor, Dr Ackermann, it occurred to me that he was just like an absent-minded professor from a children’s book. His greying hair was generally unkempt, his white coat was creased and the glasses perched on his nose hid his eyes from view. He smelled of pipe smoke, which is how people often knew where he was at any given moment. I liked that because that made it possible to get out of his way.

On his rounds, he would pick up the pictures that I had painted to look at them. I snatched them away from him. That was too intimate for me! He might well have needed to potter about in my veins, but not in my creativity! When I hid the pictures under the blanket, he would look at me in shock with his hand still outstretched. He was absolutely paralysed and I understood that my behaviour hurt him. That was new. I was capable of hurting his feelings! The doctor! The alien! If I was able to wound him then he had to be on an equal footing with me! Instead of being an interesting case, a child without a say, I had become an actor!

The germ of trust in this man, that we children called “Acki”, began to sprout. I started taking about myself, about my pains, my fear of the needle and bad prospects. Dr Ackermann did not fob me off by saying “everything will be all right”. Instead he was ruthlessly honest. For me, as a 13-year-old
girl, that was the highest form of respect that a doctor paid me. Being honest.

Acki had no time for tears. Instead of comfort and handkerchiefs, there were challenges like listening to my inner voice, recognising my own needs and trusting myself – because not every therapy suggested by a doctor was actually appropriate. In the past, other clinics have shown this and I bear the proofs of this in the deformities that I still have in my hands.

Knee punctures made me scream and howl. Acki did not scold me but remarked drily, “Your neighbour in the ward is waiting outside and she is younger than you. You’ll make her afraid.” I didn’t want that and so I pulled myself together. Caring about other people…

That’s what he was teaching me by saying that. And after the puncture, he would say, “Many congratulations, you have broken a record holder. By this, I don’t mean free periods in the lesson timetable or more time to write class assignments but recognising the social skills that I learnt through my illness. At the time, of course, that’s not what I called them, but I understood that I was certainly entitled to hold my head up straight and self-confidently, even if the rest of my body was twisted and painful.

Through Dr Ackermann’s instructions to listen to myself, I gained control over my situation. He did not gloss over where I was starting from, nor did he say I was crazy when I set goals for myself that I would never be able to achieve. He taught me to follow my goals but not to fix my gaze on the unattainable. That would only discourage me on my way. I was to concentrate on the little steps and stages, and aim for these.

Without anyone needing to point me in the right direction, another achievable way opened up for me. I never did become a reporter in Chile, but I did complete my studies in German and journalism. And that despite my teacher at the time taking bets on whether I would ever manage to do my A levels. I was to concentrate on the little steps and stages, and aim for these.

During my teenage years, Acki’s and my opinions often clashed. We often argued over political topics, though disputes were also a game between us – a mixture of teasing, serious exchanges of views and a type of mutual liking.

Each dispute fuelled my maturation process towards independence.

Acki is dead now. He died last summer. We stayed in contact throughout the years. I had known him for over 30 years. Through social networks I asked former patients whether we should put into words what our ward doctor had meant to us for his funeral. Plenty of contributions trickled in, some of them from children from different decades whom I had never known!

I could see myself reflected in all their messages. These people expressed in words what “Our Acki” had embodied for me. “Life saver”, “Second dad”, “Confidant”, “inspirational”, “a bit crazy”; but a HUMAN BEING JUST LIKE US!

“Without respect and empathy, the best training qualifications amount to nothing.”

Overcoming challenges, accepting the illness without being defeated by it – that is what we learnt from him. Without him, we would probably never have seen the fragrance of pipe smoke as something good, and many of us might never be playing chess today. Without “Our Acki”, none of us would have become the people that we are today.

Dr Ackermann had no children of his own and yet, at the same time, he had more than you could believe possible. That’s us – his former patients from several decades! All of us with a firm footing in life, even if our stability is based on rheumatic feet or prosthetics. We have all succeeded in getting our lives and illnesses under our own control.

Doctors are not gods in white, not aliens – they are people from my planet and, if they want to, they also speak my language. I learnt that from Dr Ackermann.

Without respect and empathy, the best medical or therapeutic training qualifications amount to nothing. Acki already possessed these tools at a time, in the 1980s, when people in many places still thought that rheumatism was an old person’s disease and that sick children were just interesting cases. To me, a handicapped little girl, he restored my self-esteem and my dignity. His eye-to-eye encounters with me helped me and hundreds of other sick children to discover and nurture new capabilities within ourselves – ruthless optimism, toughness and a belief in myself. And belief in a happy ending. Despite rheumatism. Or precisely because of it.