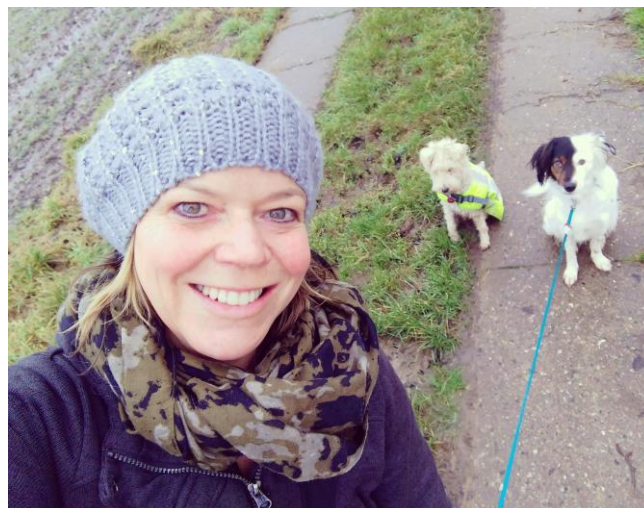


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fighting rheumatic & musculoskeletal
diseases together

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3rd place: Maiken Brathe, Germany

“My name is Maiken, I’m 47 years old and I live just north of Hamburg in Germany. Because

I’ve had polyarthritis in all of my joints since 1980, I am unable to carry out paid work, but I hold qualifications in German and journalism, and currently work as an author.

I’m a passionate photographer, Instagram and Facebook activist and, above all, I love living with my dogs.

I found out about the Edgar Stene prize through the magazine “mobil” published by the Deutsche Rheuma-Liga. I like to write about my experiences of living with a chronic disease in the hope that I can help others to take a positive approach to their illness”.

My personal champion – supporting my everyday life with a rheumatic and musculoskeletal disease

She ought to wear a red cape as she whizzes through Munich in her electric wheelchair, because Concetta is my personal champion. Anyone who has seen this superwoman would probably agree. It’s hard to believe that so much vitality can be packed into a body just 1.46m tall.

I met Concetta over 30 years ago at a hospital for children with rheumatic diseases. I was 16 years old at the time and had been suffering from polyarthritis in all of my joints for years. It was at this hospital that I had learned to walk again, but like all the other patients – children and grown-ups alike – I was struggling with homesickness. Concetta had just turned 10 and was much more self-confident than I was at the time. Her illness is extremely rare – juvenile dermatomyositis – and Concetta was dependant on round-the-clock support. Back then, I was very uncertain about how I should approach her because it hurt to see her in such bad health. But, at the same time, I found it tremendously annoying that this little Italian girl stuck to me like a limpet, always wanting to know what I was doing, if she could come with me, if we could do something together...

Even if I sometimes rolled my eyes each time Concetta popped up in front of me, I understood that this girl wanted me to do something that I had never had to do before: care for somebody else. As I'd spent my life being the permanent object of care, this was an important step for me towards independence and becoming an adult. Concetta never asked herself whether or not I would be able to take care of her. And it took many years for me to realise that I could.

For over 20 years, we lost contact and developed independently into self-confident women who were able to finish their studies and find their places in the world despite being severely disabled and suffering from illnesses. But still, there was something missing. I needed someone who didn't need an explanation of how traumatising hospital stays can be, how degrading it feels to be treated as an object in medical theatres, and how hurtful it can be sometimes when someone stares at you as though you're from another planet. Or how shaken you feel when a kid in the street unexpectedly mocks you with abusive words.

When I got a letter from Concetta in 2008 saying that she was organising a reunion for everyone who had been at the children's hospital for rheumatism, I couldn't stop myself from crying. If I'm honest, I didn't think my annoying little friend would have survived because of the severity of her illness. After more than 20 years, we finally came face-to-face with each other once again – and, this time, it really was face-to-face despite a height difference of 26cm.

Our reunion really touched me. It was a crucial experience for me as it showed what was missing from my life with “healthy” people: exchanges with someone who shares the same experiences as me! Someone who doesn't need an explanation of why some days I can't open a door; someone who reaches for the sugar in a coffee shop with the same crooked fingers as me; someone who doesn't comment that sugar is bad for rheumatism and that I should watch what I eat because they've read it somewhere and are “only trying to help”.

After that reunion we vowed to stay in contact this time. But, as is so often the case, the countless kilometres came between us. There are more than 900km separating Concetta and me and neither of us enjoys speaking on the phone. Holding a telephone causes a lot of pain in the hands and elbows. Speaking openly also means being alone, which proved nothing short of a logistical miracle for someone who requires 24-hour care and has an overprotective ex-partner. Then there was the task of finding a moment when neither of us was too exhausted to properly engage in conversation with the other.

But we managed to find the perfect alternative: for three years, we've been sending each other voice messages using our smartphones. Each day, we tell each other anecdotes about our daily experiences and, when we're feeling lonely, we sit together (virtually) at the dining table and listen to each other's news while we eat. Most of all, we're there for each other when one of us feels misunderstood, or when our fears of the illness and death loom before us like an invisible tiger

roaming around the room. With Concetta, I talk about the tiger, give it a pet name and, eventually, tame it. Naming the fear makes it less scary for me.

I avoid speaking about this with the other people around me. Certain friends feel overwhelmed – most only show a certain level of concern then withdraw because they don't want to be confronted by the thought of illness. When I was a child, my mother brought me comfort and took away the fear of death, softly whispering "everything will be OK". Then, once I became an adult, I understood that my mother's words were just a formula, because she wasn't in a position to be able to assess the situation. My mother passed away six years ago and, even though I'm now a woman in her 40s, I was still missing that one person who didn't need an explanation of my ordeal of living with a chronic illness.

Now I have my little friend by my side—well, at the other end of the country. I have Concetta to help me ward off my fears. The simple act of expressing my fears means I get to do a tremendous amount of self-reflection which helps me to collect my thoughts. Putting these thoughts into words helps shine a new light on everything and helps me to separate emotions from facts.

Concetta is a woman who has been through a lot. She has the skills and experience to conquer tigers, evaluates the facts with me and helps me maintain an objective perspective on things. She consoles me, but not with the "everything will be OK" formula that has now lost its magic. In her I have found my confidante who is there for me at the drop of a hat, my lifeline, my own first aid kit. She says to me: "Maiken, don't lose your head about it, try to think clearly. I'm here for you whenever you need me." And that's exactly what I need in the moment.

Concetta and I are like identical twins separated at birth – and by the stretch of Germany that lies between us. It doesn't matter that she's short and I'm tall, that she's from the south and I'm from the north. We became kindred spirits in our childhood as a result of shared experience. I call her my "journal" because she's been by my side through my fears and she's helped me through other troubles in life: separation, illness, moving, a new beginning. She calls me her "cortisone" because she needs a daily dose to give her the boost to get through the day. Together, we've developed a Plan B for our lives. We make jokes over Instagram, share these thoughts with others and show people that there's always a Plan B in life, even if we don't think we can carry on.

I'm a personal champion for Concetta too, a heroine of sorts, even though red isn't my colour. I still think they should make the cape in size "S" though. Because my little friend is so great and powerful, she can easily tame ferocious tigers and overcome 900km.