

Edgar Stene Prize 2018

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

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It is difficult to unequivocally declare who (or what) the champion supporting my everyday life with my disease is. If I were to suggest a person, I could not name only one. If I were to suggest something metaphysical, I also could not name anything specific. I do not believe in a god, and I do not follow any religion or cult of any person, creature or thing. The champion is not even one particular animal. There have been a number of champions during the 16 years I have been living with the disease. Each of them has left a mark on me, consciously or not, leading me to a specific path and bringing me to where I am now.

When I was diagnosed with systemic lupus erythematosus (SLE) at the age of 21, the very first people who supported me then – and who have been supporting me all the time – were my parents and my sister. They have provided reassurance during difficult times, sometimes telling me off for being negative. They have shown me how to look for other solutions.

Every day they prove that they love me despite the physical distance. They have given me the “tools” (as it is now commonly described, not only in professional jargon) to “manage myself”. This means that they suggest books, articles or films online which allow me access to the opinions and knowledge of others. They talk to me about life and what the most important things in our lives are.

Back then, another important person for a girl who went through a shock following her diagnosis – and who was wondering about what her life would be like (also her sexual life), how she could be attractive with the disease – was her first partner. We met where else than at the hospital for rheumatic diseases. He – as well as other partners since – proved to me that what is attractive is inside us, not outside.

It is not important what you may look like at a particular moment, if your joints are swollen and you cannot move, if your face and body are covered in red blotches, your hair is falling out and you have bald patches on your head... What is important is your attitude towards others, what you represent, and whether others want to be around you because of your sense of humour or what you have to say.

My main doctors – a rheumatologist and a haematologist – have also been my champions. Medicine really is their calling. I only found them a number of years after the diagnosis. They treat me as an individual, not just another patient. They know what works for me and what does not; they remember the bad times but also know what it is like when things are fine – and they do all

they can to make that happen. I have cried in their offices many a time. They have always provided me with expert advice and not just empty consolations that “it will be OK”.

When the disease was particularly active, my rheumatologist would even call me to ask how I was and if the new medication was helping. My doctors have shown me how to manage my disease in medical terms. They have shown me that there are good times following the bad, but also that, due to the nature of my disease, I must be prepared that things may get worse.

My friends are also my champions. I can always confide in them when I have a dilemma – and I have plenty of those because SLE is not just a physical, external condition. It also brings mood swings, constant uncertainty and anxiety or depressive episodes. Friends provide moral support. They visit me and console. It is incredibly important to me.

Random people I meet may become champions – sometimes unconsciously. Someone tells me a story which makes me think; someone does something nice which turns out to be of great help to me... Even people who are not friendly or supportive may turn out to be champions because we learn something from them, we draw conclusions. I also have such champions.

I said earlier that it is not only people who are champions. Animals are equally my champions: my dog, cat and horses. The dog, Huzar, is my personal trainer; he “tells” me every day that it is time to exercise. It is thanks to him that I can walk normally, that I am in shape and control my weight. Horses also support my fitness but are, equally, therapists for my soul. When pain would almost make my muscles and joints burst, when I was unable to get up on a horse alone, they would give me the most precious thing they could offer – the warmth of their back, their peacefulness and understanding. Finally, my cat, Gremlina, a gift from my sister, knows when I am in pain and where it hurts. Her soothing purring and warmth make the pain go away from any given spot.

Lastly, my metaphysical champion is my own spirituality: my views and thoughts which I have developed thanks to the signposting of the above-mentioned champions.

We ourselves have to learn to live with our disease. People and animals may not be around forever. What we have learnt and received from them will remain. The most important thing is to learn to manage your disease, to know where to look for help and to teach yourself to access your own consciousness and tell yourself: “It will be fine. You know that.”