

Edgar Stene Prize 2017

Winning Essay: Diagnosis from the perspective of a child

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A seven-year-old child with her whole life still ahead of her. Dreaming, perhaps, of becoming a dolphin trainer or veterinarian. A talented dancer, enjoying a carefree lifestyle and a future without limits. Until one day, she tells her mother that her feet and knees are hurting. Her mother, refusing to waste a single minute, took her to the doctor who found nothing wrong and told her: *“Don’t worry madam, your daughter is fine”*.

The daughter, now in her first year of school, was no longer able to dance. The pain became too much for her, and she had to leave her dancing shoes in the cupboard – only the first of many sacrifices she was to make.

After an entirely normal day at school, she told her mother that her hands were now hurting too. The unbearable pain in her wrists was making her fingers cramp. She was no longer able to go to school because the overwhelming pain meant she could not write. Following another trip to the hospital, and many tests later, her mother was once again told: *“Don’t worry madam, your daughter is fine”*.

The girl was kept home more and more often because sometimes she simply could not go to school. Her feet, knees and hands limited her with invisible shackles of pain. She was visited in her home by tutors, because she would otherwise be unable to obtain her leaving qualification. Forced on by the pain, fighting against her continuing restrictions, she still had to go to school. Even though she was no longer able to cycle, could no longer use the school stairs and had fallen out of pace with her peers, she passed her final exams with flying colours. Without any help, as the doctors kept saying: *“Don’t worry, madam, your daughter is fine”*.

She went on to university as she wanted to make a difference in the world by studying artistic therapy. Her new dream for the future was to help people. But from this point onwards, her dreams became a fleeting fog in a darkening world of pain and fatigue. She kept visiting doctors – it was difficult for them to maintain that there was nothing wrong with her as her body told a different story.

Her joints felt as though they were being stabbed. A growing set of pain, fatigue and limitations started to govern her life. However, she kept on going without receiving any help. Because the doctors told her and her mother every time: *“Don’t worry madam, your daughter is fine”*.

The young woman graduated, and was proud to receive her Bachelor’s degree. She had to fight a lot, give up a lot, and overcome the depression brought on by the pain. But, in spite of everything, she got through it all! Despite the lack of understanding from her doctors and the lack of medical assistance, she had fought and won.

Unfortunately, her dream of offering her assistance as a therapist was not to come true. Once again, her plans for the future burst like a bubble – just as they had done many years ago when she was at school. Work became hell. She lost one job after another because of the pain that followed hot on her heels.

Twenty-one years later, the doctors were still saying to her: *“Don’t worry madam, you’re fine”*. Disillusioned by the medical world, she soldiered on with the only drug that the doctors could offer her: *“Learn to live with it”*.

Acceptance.

Easy to say by those not suffering from it. They felt no need to fight against the pain and the depression caused by her loss of mobility and future prospects. By this point, her whole body was consumed by pain and fatigue as a result of the increased number of joints falling victim to her parade of agony. Fitting into society proved an impossible task. At that point, she decided that enough was enough.

A rheumatologist at the local hospital examined her and her medical records for what seemed the 100th time and, after a physical examination, came up with an answer: fibromyalgia. After 20 years – and a seemingly endless fight – she finally had a diagnosis!

I was this girl, this woman.

Would my life have been any different if the doctors had listened to me, as this rheumatologist had? If they had looked at me, the one who was suffering, rather than the results on their papers? I’m sure of it. They couldn’t cure me – there is still no cure for fibromyalgia. But they could at least offer me recognition... Recognition of my suffering and my continuing battle. That could have made a real difference in my darkest days when I felt abandoned and alone – all because the doctors kept telling me: *“There’s nothing wrong with you”*. Nobody listened to me, and I felt as though nobody was taking me seriously. Twenty years on, doctors acted as though there was nothing wrong with me, as though I was making it all up. That it was “all in my mind”.

My life could have been so different had I not had to fight against both my illness and a lack of understanding from the medical world. It could have been so much help to me if they had said: *“Even though this might not mean much in a medical sense, you should know that I hear you, I see you, I recognise your pain...”*