OVERCOMING THE CHALLENGES OF GETTING AROUND WITH A RHEUMATIC OR MUSCULOSKELETAL DISEASE



Sister Anastasia



With my family



Working in the monastery gardens

Sister Anastasia - Kalina Petrova Evangelatova Bulgaria

I have lived in the Dragalevski Monastery since 1997. The monastery is located at the foot of the Vitosha Mountain in Sofia. I graduated in theology at the University of Sofia and after my graduation I lectured on religion in several high schools. My parents were actors and I am very sad to say that they are unfortunately no longer with us today.

I have various daily responsibilities in the monastery as it is one of the most visited places in Sofia and in Bulgaria overall. To do my job well I need to be physically active.

I am happy that I found wonderful friends in the Bulgarian Ankylosing Spondylitis Patient Society and the Organisation for Patients with Rheumatic Diseases. Together we work to improve the quality of life of people with our problems. In my spare time I share my difficulties and experience in life in my personal blog http://evangelat.blogspot.com I like the idea of sharing and of telling others about the problems caused by the disease, not succumbing to resentment or pessimism, but rationalising it as part of life.

Overcoming the challenges of getting around with a rheumatic or musculoskeletal disease

I don't know much about plants, but I admire beautiful gardens where different flowers bloom and change with the seasons. I never imagined I could tend to them myself, but now nurturing flowers is part of my life raking pebbles out of the soil, fertilising, watering and weeding. Having to tend to plants has helped me achieve the impossible - to 'treat' myself by forgetting about me. They have taught me a new inner experience and beauty.

I was 23 when I started to feel searing pains in my spine and legs. I never suspected that one day I could become stiff and crooked like a Japanese bonsai, or that something so natural – movement – would turn into such

a trial. The pain that developed and took me over seemed unnatural, impossible, unreal!

Ever since I was a little girl, I was always full of beans and soon developed an enthusiasm for different sports, including swimming, volleyball, table tennis, badminton and ice skating. I was quick to master the mechanics of movement, and was always trying out new ways to keep my balance and get faster. The onset of my disease coincided with my life decision to take my vows at a monastery on Vitosha Mountain, not far from Sofia. There is no public transport to the monastery, and the rare buses in that direction stop far away. I often had to walk down from the village and back because my elderly father remained living alone in the city. I liked to bring him pure spring water from the monastery, but the pain in my spine worsened. Although I had to stop taking my heavy backpack with me, I still went down the mountain. The pain made me start to faint whenever I tried to hurry. I would suddenly collapse to the ground and cry helplessly. The doctors prescribed physiotherapy, radiotherapy and medication. I

chose a sanatorium near the monastery and asked to be an out-patient so that I could carry on with my work, but I had overestimated my strength. Although the monastery was an hour's walk from the sanatorium. it would take me much longer. Alone on the mountain, gasping from pain, I would carry on agonisingly and slowly. The treatment made me feel better and when it was over, something clicked and I regained control over my legs. Walking was still painful, but I was no longer falling over!

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I went on with my daily work in the monastery gardens, which were arranged on different







Me and my friends from BOPRD

terraces. We would remove stones in buckets, and use a wheelbarrow to bring new, rich soil from the forest and sand to make the soil viable. I wore a corset to support my lower back. It was painful, but I wasn't giving up! At the time I somehow sensed that this was my only therapy. In my thoughts I associated the rotting compost and manure we carried with my pain; it may be nasty, horrible stuff to handle, but it helps the flowers grow and give off their fragrance. The pain fed my willpower and taught me perseverance and patience, but it also often made me irritable and rude to people. After such episodes, I realised the strength of the inner hurt I was causing others and that I had no right to take my pain out on them. From dealing with the 'rotten manure of pain' I had accumulated over the years, I learned that suffering, grief and fear confuse you, and make you rude and irritable. But I could and had to change this and learn to persist and even to smile! I gradually realised that overcoming the hardest and most problematic moments in my life had come from the 'rotten manure', which had nourished my character and willpower and

taught me to appreciate the little things in life; it opened my senses to see and empathise with the pain of others.

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Years later, because of recurring eye infections – iridocyclitis – I found out my real diagnosis – ankylosing spondylitis. Some doctors convincingly rejected my diagnosis. This confused me, but by now we had the Internet at the monastery and I logged onto medical websites with forums and discussions for patients with rheumatic conditions. I read a great deal and was convinced that what I had experienced over the

years corresponded precisely with the symptoms of ankylosing spondylitis.

Unexpectedly, in the midst of the pain, the gloomy prognosis of the disease and the 'rotten manure', I also found beauty: instead of flowers I found people who, like me, were suffering from the disease, but wanted to share their time and compassion to support others, and to improve their ability to access treatments. Out of the pain and the 'nourishing manure' in my soul arose gratitude and the belief that my suffering has not been in vain. I saw another side to life and realised that there are others who, like me, do not give up but carry on struggling on a daily basis, giving their all to help others and to nurture their spiritual beauty and fragrance, just like flowers.

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Editors notes on English terminology:

Compost – organic matter left to rot and then used to fertilise soil

Manure – animal dung used to fertilise and enrich soil