



Mr. John's story

Until I was 50, I was a very active sportsman. I canoed on whitewater, climbed mountains at home and in the Alps, trekked in the Himalayas, ran long distance and marathons; I rode my bike 75 kilometers to work; and I showed my back to 30-year-olds in athletic meets, mainly the one mile, which was my favorite and which, back then, I could run in under 5 minutes. But all of a sudden, my back started to hurt, I would get more and more tired and sometimes my rib would

break when I was tying my shoelaces. I thought it was not quite normal, but instead of going to the doctor, I took paracetamol for a week and then the hard training would let my body forget the pain.

And so my multiple myeloma, the monster I had been nursing this way, developed in peace, and the pains in my back and ribs, where the body produces blood, progressed so far that I had multiple rib fractures, not even counting the microscopic cracks, and three broken vertebrae. One fell apart completely and there was a danger that my spinal cord would start to look for another way through. The pain was insufferable and I started to choke. My long-suffering rib cage went on strike and my muscles of respiration, even though they work on a vegetative basis, could no longer order my broken ribs to move up and down. The spasm in my chest was like an anvil and my breathing reduced to a minimum allowed by the non-expanding chest. I was no longer able to walk, so I was carried down into a car and driven to the hospital. There, I was diagnosed with multiple myeloma with a extensive involvement of my bones. My entire skeleton was as if eaten by woodworms and I only retained movement in my hands but the worst part was the horrible fear of choking. The room was full of air, oxygen in my nose was on all the way and I couldn't breathe in. That was a really frightening feeling – to be choking...

Thankfully, the doctors in the Faculty hospital in Karlovo náměstí in Prague immediately started me on chemotherapy. I had very little time in this limbo. And the time I had was difficult, I saw many things in my life from a new perspective. The persistent fight for every breath. The chaos in my head. The fear and uncertainty whether I will breathe again. I was a bed ridden, barely breathing. And I had to make peace with giving up my unfulfilled and unfinished life plans which were, in that moment, not viable. In spite of all the excellent care I was receiving I also very strongly felt the loss of dignity, as nurses had to administer a bed pan and wash my rear after bowel movements. Chemotherapy helped slow down the myeloma but my damaged bones were a sad memento. With my spine broken several times over and my bones full of holes, my prospects for an active life diminished. I categorically needed surgery on my spine, which I underwent at the Military hospital in Prague. If it had been unsuccessful, I would have been in a wheelchair for the rest of my life. For me, an active person, father of a family, son of parents, and a social person throughout, it meant a farewell. Farewell to the unreached goals of my life. I realized I would never again climb a mountain, never canoe through rapids, never run a marathon. I would have to forget riding my bike but also going to the woods and picking mushrooms, hikes and camping. But then the

doctors in Střešovice cast two of my vertebrae with a ceramic material in order to support my spinal cord better, and they did it so well that my prospects broadened a little bit again.

I had to learn to walk again, like a little child. I did it with the doggedness of an ex-sportsman. After six months, my attending doctor referred me to a bone marrow transplant, which, in the case of us myeloma patients, is in the form of an "autotransplant". The preparatory phase, separation of the cells and the insertion of the cells back into my body all went well and the new cells started working better than the old, infected ones.

Due to the complications caused by my broken bones, this journey lasted from April of 2009 to March of 2010, when I went back to work. I work as an IT auditor in a large bank and thanks to the company's understanding and a great team of coworkers, my job waited for me. Even though I qualified for at least a partial disability pension and concessions at work, I didn't take advantage of any of it and went back to work as before. That's partially because I hate to fill out complicated forms and I don't want to look like a suspicious person, asking for inappropriate benefits. I tried to apply for a severe disability status but in spite of having a recommendation from my GP and many reports from medical experts, the officer who came to see me at home asked if I can tie my shoelaces and if I can feed myself, and when I told her I travel 75 kilometers to work by train every day, she closed her notebook and looked at me with suspicion as if I were a fraud. She didn't understand that I could have stayed home and enjoyed the rest of my life with my family. She didn't understand that I missed my work and the company of my colleagues. Or that I wanted to put my years of experience to use, to train a couple young coworkers, that I wanted to be useful and not depend on the society for everything. She didn't understand that it takes me quite a long time to start moving my worm-eaten bones after I wake up, but because I work, I contribute to the GDP of this beautiful country and I pay considerable taxes to the government...

This experience with my illness, which the Internet deems incurable, was incredibly valuable to me. It was, in a way, a gift. I reassessed many things in my life. Many priorities shifted and I started to value relationships instead of things. When I was lying in the hospital expecting the end of my life, I realized that money, possessions, the car, the house I started building or the summer house are not worth what I had previously thought them to be. My position at work, influence on the others, even my intelligence or knowledge and capabilities no longer carry the same weight I previously ascribed them. Looking at my puzzled family, ready to say good bye to me, and the helplessness and despair in the eyes of those close to me, I realized very

strongly that what remains until you die are relationships. And love.

I realized that if I give all my money away, I will have none left.

If I give all my possessions away, I will have nothing.

If I give my home to someone else, I will become homeless.

If I give away my power at the company, I will be powerless.

Only when giving love, friendship and fellowship does something unusual happen. The love is not diminished. I have no less of it. It adds up and sometimes multiplies. I don't have to be thrifty with it. The more I give away, the more I receive... that's the paradox of love and friendship.

And so, after I returned from the hospital, I wanted to give back to life. I thought about it and found an organization called Amélie, which is an association of volunteers who help oncology patients in their spare time. Once a week after work I go to a hospital and I am privileged that it can be the same hospital where they helped me so much – the Faculty hospital in Karlovo náměstí. I come to talk to patients about life, the weather and the joys and hardships of life. Well, only with those who feel like talking. It is great encouragement for me and I hope it is for the patients, too. I often discover deep and amazing people and my example, the fact that I came out alive from a situation similar to the one they find themselves in, I hope to give them some hope.

I also started with sport again. I will never run a marathon, but I started walking. At first, I was inspired by my friend Jirka, with whom I was at the hospital for the bone marrow transplant and who kept inviting me to walk the pilgrimage to Santiago de Compostela. Somehow, we didn't manage it in 2011. And Jirka's multiple myeloma returned early and he died in 2013. When he was still alive, I promised to myself that I would do it alone, in honor of him. And so, one day, I decided and within 14 days I was on the road. I set out from Lourdes in France in November, through the Pyrenees and the beautiful Basque country and after a month I reached Santiago, about 1000 km away. It was a lot for my back but my myeloma must have liked it because it stopped bothering me and my values calmed down.

In 2014, I happily set out for another pilgrimage. I took my entire vacation time and added more and after 40 days of walking, I made it from Prague to Rome. I walked through Šumava at its most beautiful in April, around Inn, through Salzburg and the high Alps including the Grossglockner, it was all an amazing prize. And then the beautiful craggy Dolomites... At the end, I walked the Way of St. Francis through the Apennines through La Verna and Assisi all the way to Rome, where I was meeting pilgrims from all over the world. We keep in touch and I have more and more friends, for which I am very glad. When I was

leaving for this pilgrimage, my doctor was saying that my myeloma values were edging towards another transplant. In spite of that, when I promised I wouldn't overly exert myself, he approved of my pilgrimage. When I returned, to everybody's astonishment, my values were lower than when I left.

The disease does have its laws and I won't be able to fool it forever. In 2015, 6 years after my original diagnosis, the level of paraprotein which signals the number of cancer cells in my blood rose so high that active treatment was needed again. Tests showed that I could withstand another bone marrow transplant and my health insurance company agreed to this costly procedure. And so, in May 2015, I arrived at the transplantation clinic. The transplant was unusually successful and my new blood stem cells were healing at an unexpected rate. The problem, however, came when I was ready to leave the hospital two weeks later. I had alternating high fevers and rigors, three times a day. It was clear that my weakened body with almost no immunity had developed an infection. Many tests later, they found a lump on the valve of my heart, about 2 cm long, which was threatening to block an important artery. The decision was quick. At noon, I signed my consent to a heart surgery and watched the worried faces of the hematologist, anesthesiologist and surgeon, who warned me that with no immunity, opening my chest and heart was risky, but that it should be undertaken nonetheless. And so I went into the operating theater. A short prayer before they put me under and then the doctors opened up my chest and my heart, took out the affected mitral valve and gave me a new one. From a pig.

And so I found myself again in a hospital bed, breathing with difficulty, and again (so many times already) the nurses were helping me to slowly learn to walk. Then it went fast. Spa treatment in Poděbrady, a slow convalescence and an even slower increase of the strain on my body. I re-learned to walk up stairs, taking a short break at every other step... And then I went to the audit doctor to get an extension for my severe disability card. He read the tall pile of medical reports and reached the conclusion that I was ready for a disability pension with the ability to work at a maximum of 30 % intensity, in exceptional mode.

My work was understanding and adjusted my contract to match the doctor-approved intensity. They allowed me to do most of my work of an IT analyst from home, over the internet. I still feel needed for work tasks, for which I am very grateful. Every new day makes me happy and if at all possible, I will pass the happiness on. My coworkers look forward to my presence there.

I am grateful for everything life has given me and keeps giving. Every day; every step I realize I could have been unable to make; every breath, because I

lived through the horror of not being able to take it... I am grateful for my family, my daughter who makes me happy, my elderly mother and for being able to take care of her, and that I have so many friends and am making more...

I am also grateful that I found solid footing, joy in my life and the faith in God, who must surely love me. My gratitude can be impossible to express and so sometimes, I just take in this beautiful world.

Your Honza, aged 58

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