



Rita Gruber
Hungary

Bike tour with my friends



On top of the world. We succeeded!

Living a full life

I am Rita Gruber and I am 34 years old. I was a hairdresser by profession, but now I am a high school student. Nowadays I live in Budapest with my friend. I am lonely – I have lost my family members.

I regularly visit the website www.bechterewes.hu which is the website of the Hungarian Bechterew Association and is where I got the information about the competition. I wrote my essay because it is good to tell that there is always a way out of problems.

My father died eight years ago, he was a cancer patient, and I lost my mother in September, she had an orphan autoimmune disease. I kept her company to the end. Writing about my life helps me, I am still here, life counts with me and I count with life.

I live with a locomotor (rheumatological) disorder. How do I try to lead a full, enjoyable life with it? The symptoms started when I was an adolescent, but I didn't see a doctor for a long time because I really didn't think it was anything serious. The first thing was that I had inflammation of the iris while I was at secondary school. My family couldn't understand it. I underwent treatment, and it went just as it had come. We soon got over it.

I must have been 16 or 17 when I had shooting pains in my waist that kept coming back. We all thought I was growing. The problems were mild to begin with, and they soon passed. Later on these phases became longer, but they were interrupted when I took more regular exercise, which somehow prevented them.

I reached a point where I couldn't fail to notice that something wasn't right with me. That was when I went to an orthopaedist for the first time, who immediately referred me to a rheumatologist. That was followed by tests, and then waiting. It is not a time that I remember with fondness.

"I wasn't going to settle for that"

I have known that I "suffer" from Bechterew's disease since I was 22. I say "suffer" in quotation marks because I cannot live with the idea that I am suffering in some way, or that I have been struck down by something. I would prefer to say that I live with it. It has been a long journey up to this point. Twelve years have passed since my diagnosis, and I have gone through various phases since then, both mentally and physically.

I will never forget the day when the doctor told me what my illness was. My first question was "what could I expect in relation to my future?". I was given a short answer – too short for such a serious question. It was only five words: "I'm not a fortune teller". I have always

been stubborn, and I wasn't going to settle for that. I consulted several doctors, believing that there had been some kind of misunderstanding and that they were all wrong. It's clear now that they were right.

I wanted to know about the future, and always asked what I should prepare myself for. I remember the feeling when the dreams I had woven for my life were suddenly pulled out from under my feet. Then there were the treatments, the medicines, and the days and weeks spent in hospital. There was no significant change in my condition and, when I was 23 or 24, I was pensioned off and had to give up my career. The huge amount of free time that I had was a burden, and aimless thoughts ran around inside my head. I let myself sink into self-pity. I was in pain.

"I felt I was living in a prison"

During the most difficult phase, my mother helped me put my socks and shoes on. The space around me became more confined and I felt I was living in a prison. I felt I had no prospects and that my life had no meaning. I was discontented and fought against the circumstances. Maybe I'd had enough of myself because, ultimately, I was overcome by something else: the desire to live. A sense of obstinacy and instinctive resistance was aroused in me; I wasn't going to end my days not having even tried. I sought some meaning, a way to move forward... Something to give me a goal.

That's when I saw the advert for a hospice, which was looking for volunteers. I don't know what made me go to them. Back then, I was afraid of everyone and everything, but I still got over myself and went for the interview. I underwent training, as part of which we were treated by a psychologist and performed various exercises as a group. I went so that my existence would have some meaning, so that I could help.

"I didn't want to upset my family"

In the meantime, the thing I had least expected happened. I slowly got better. I was finally able to speak freely about my disease at the preparatory classes. I didn't dare to be honest at home, because I didn't want to upset my family. But in the group, and in front of the expert, I could. As the other members of the group were also affected by some kind of health problem, we could share our experiences. Some of them were recovering from cancer.

At one of the classes, we were given the task of drawing a picture of what sickness meant to us. I drew prison bars. I thought that sickness always closed everyone in. To my very great surprise, an older lady drew a flower. I didn't understand. I could not have understood then. During my volunteering, I spoke to people who had tumours, and those conversations made a deep impression on me. One afternoon, I was sitting on the bus home. It was still cold, but the sun was shining in through the window.

I turned towards the light, and smiled. For the first time in a very, very long time, I felt that life was good, despite everything, that I was lucky. That was when I realised that "I have been struck down by a disease" had changed into "There's a condition that I live with". I live with it, but not in it.

The people around me, who had lived their lives through great suffering because of their tumorous diseases, had shown me that I should love life and love the days that I have – the days that I have right now. Of course it isn't that easy to do, but my attitude has changed. Loving life has become my philosophy for living. I have learned to dance, even though participating in the classes was different for me than for the others. I felt my boundaries, but I was there all the same. I loved running, but now I can't. Despite this, I ran a relay marathon three years ago. I was very slow and our team came last, but it didn't bother me in the slightest. Years before that, I had wondered how I would ever get up after sitting down, so in comparison with that it was a victory in itself.

"Loving life has become my philosophy"

I can honestly say that I have now managed to do everything that I've been drawn to. Bechterew's disease has not imprisoned me, but has given me opportunities. That's why I've been throwing myself into things for several years – to prove to myself that I'm capable of doing them. Everything I do

now stems from the self-awareness I have gained from my many experiences, and I can thank my condition for that. But the pain that rears its head again and again does not let me forget that I have a "companion" on this journey and, at the same time, it reminds me how much strength I am capable of mobilising if necessary.

I don't know what tomorrow will bring. I don't ask anyone anymore because doctors represent science, which definitely cannot give an answer for everything and it does not tell anyone's fortune. I don't either. I don't guess, I don't look very far ahead; I just pay attention to the bends in the road that I can see. I do look back from time to time, but only to remind myself where I started from.

I'm 34 years old. I'm in my first year of college. I don't have children and I'm not married. I am a woman who is living a full life. And I happen to have Bechterew's disease.



Living a full life
Rita Gruber



With my mother