

Living with MS

Yağmur Bozkurt, one of our PhD students contacted her friend from Istanbul, who was diagnosed and has been living with MS. Although her friend chose to remain anonymous, he/she accepted to share his/her story and experience during the COVID-19 breakout.

1) When were you first diagnosed? When were you given your official MS diagnosis?

The disease was first diagnosed by mid-2017, after a series of check-ups and consultations from various doctors.

2) Did your diagnosis take a long time?

At first, I was admitted to the hospital where various tests were conducted. It took approximately three months.

3) What kind of tests did they do to get the diagnosis?

Well, starting with the common one, which was an MRI scan. While I was admitted to the hospital, they also collected some fluid out of my spinal cord. Moreover, blood tests and evoked potential tests were also conducted.

4) What was your reaction after hearing your diagnosis?

At first, I was oblivious to what the doctor was saying. Neither of my parents had any clue, as it was the first time, we heard about such a disease.

5) What sorts of symptoms do you or have you experienced?

At the initial stage, the first symptom was double vision (diplopia). After consultation with a doctor, and consuming vitamin B12 for almost two weeks, that symptom tended to disappear. After one year, I started to experience symptoms like unnecessary fatigue and numbness under my feet.

6) What meds, treatments or alternative therapies have helped you the most?

I am taking a disease modifying drug that my doctor has prescribed. It has helped me tremendously, to such an extent that there was 80% improvement in MRI scan results after one year of my diagnosis. Apart from that, vitamin D3 supplements also played a vital role in my wellness.

7) What sort of activities/hobbies, such as yoga, do you practice to cope with your symptoms or make your life better?

Exercise and weightlifting are part of my lifestyle. Apart from that, spiritual meditation has also changed my life a lot.

8) Do you have a personal philosophy that has helped you coping with having a chronic illness?

I am grateful for what I have. It could have been worse... who knows! Stress and depression will trigger it further, so I hardly think about it and I try to keep my lifestyle as healthy and busy as possible.

9) What advice would you give to someone who has just been diagnosed with MS?

As per my assumption, the intensity of this illness varies among people. My condition wasn't that bad as compared to what some people have experienced. But still, my advice would be "Don't panic. You can live a good life despite MS. With good healthcare, a supportive family and friends, you can cope with this illness."

10) What would you like to change in the country you live in? Support groups, more awareness, and easy access to treatments, or finding jobs?

I guess awareness is a problem! I believe that there are still some people out there who may have some MS symptoms, but tend to ignore it. Even some doctors are misinformed about this chronic disease.

11) Did MS affect your career in any way?

It did, initially... as I used to get exhausted without any physical effort. But with time, it got better and with proper medication and healthy lifestyle, I managed to cope with it.

12) How did the COVID-19 lockdown affect you?

Honestly speaking, it turned out to be a blessing in disguise. I started working from home (Pakistan), which turned out to be positive, as it helped me to trim my work and focus on my personal life as well.

13) Did you get any support from the government or healthcare workers? Psychological or health-related?

Not as much. I got an appointment and support from a private doctor back home.

14) Did your doctor give you any counselling/advice specifically related to your condition and COVID-19?

He just consults me to carry on with my normal routine and to make sure I don't forget to take my meds, which I have been taking for the past three years.

15) Did you need to take any additional precautions other than wearing a mask and general hygiene?

I am taking all the necessary precautions just like anyone else. In my case, I tend to be extra cautious, due to the fact that I intake meds on a daily basis.

16) Any last thoughts?

I once asked my doctor if the disease could be reversed? He just told me that there is still a lot of research going on and there are several medicines out there that can control it. I would prefer that all doctors raise more MS awareness, as it is a serious issue. Most people are unaware of the disease. I hope that one day, we can find a solution to cure it!