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# LIVING WITH CML

Patient stories to help better understand daily life with Chronic Myeloid Leukemia (CML)



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I am [Tanja Fajon](#), Slovenian politician, [Member of the European Parliament](#), former journalist and correspondent. I was diagnosed with CML some 25 years ago. Due to my excellent doctors (I am taking glyvec, biological medicine) and my positive nature I am feeling very well and I consider myself healthy. I have a demanding job and I adore sports, especially running. My CML has never proven a burden to my life.

### How did you feel when you were diagnosed with CML?

I was shocked and I was scared. I was 25. My whole life and world were in front of me. I had my job as a journalist that I loved, I had a lot of plans. I also had a loving family and friends and with their support, I started to live fully quite soon. I have always been a strong person, CML made me even stronger. The illness takes but it can also give.



Misconceptions about leukemia, stigma, and perceptions that people with cancer either can't handle challenging work or that they will soon exit the workforce due to their chronic illness or treatment are frequently barriers to careers trajectories like yours. How did you manage your CML diagnosis and you achieve coming back to work with the disease?

At the beginning of my medical treatment, I was taking interferon, causing me a lot of pain, fever, headache. Sometimes I barely stood up, but still went to my job at the radio, giving there my best. I was lucky enough to have a supportive working team. During the following years, my illness slowly worsened and I heavily hoped for a bone marrow donor. And then a strange coincidence happened - I have got two offers: one for a dream job of correspondent in Brussels and another - a donor. At the same time, I read that in the USA, a new medicine with high hopes was been developed for CML. Finger crossed, I took the job. I did the right thing.



From your perspective, what is the best and the worst of your living with CML? Could you share with us any tips to keep your well-being as an active woman managing your disease, job, busy agendas, travels, and personal life as well?

I live a healthy life. I do not think about my disease. The only signal of my illness is my pill that I take every day and a blood test every 4 months. But it is a complete routine. I believe everyone must find his own way to wellbeing. The general recipe would probably be same as for every other individual: positive attitude, healthy food, enough sleep, relaxation. As a politician it is sometimes very difficult to obey and combine this advices but luckily, my character type helps me a lot!



As a CML patient and also Member of the European Parliament since 2009, Member of the MEPs Against Cancer group, and an active supporter of the patient advocacy community as the CML Advocates Network. In your opinion, which would be the main challenges for CML patients to face in the next year?

The next year will definitely be affected by the COVID-19 outbreak. As some CML patients might be more vulnerable to the virus, they must therefore apply security measures even more strictly. Concerning new policies, I hope that European Reference Networks will reinforce their role and that equal access to treatment will be ensured for every patient with a rare disease.



### Inspiring CML patients

How do feel as a CML patient during this global epidemic and how do you daily manage your lock-down?

I believe I have no different feeling than others. I am working from home, obeying restriction rules, wearing a mask, taking care for hygiene, and hoping that the COVID-19 danger will pass soon.

How are you living the COVID-19 outbreak? Are you going through any restriction on access to treatment or monitoring in your country?

I have no restrictions. I can get help if I need it as usual. Lucky enough, I had no special need for medical treatment.



What is the most valuable life lesson you have found out during the COVID-19 pandemic?

**Only solidarity can save the planet.**

Send your supporting comments to Tanja on Facebook by clicking this button

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