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LIVING WITH CML

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



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- Jana Pelouchová, co-founder of the CML Advocates Network and President of Diagnoza Leukemie, Czech Republic -

My name is **Jana** and I'm living my 19th year with CML and I'm enjoying it because last Christmas I have reached MR4 surrounded by my family including two grandchildren who were born during my treatment and whom I have not anticipated to see as school-children and beyond.

When I was diagnosed with CML I was completely lacking information on what my daily life would look like. I remember searching through my diary when the doctor phoned me after taking my bloods "a haematologist wants to see you" - to find a suitable time for an appointment! As if there were a good time for diagnosis. From full health into hospital bed for having leukopheresis done, and I thought, when being driven home each night (as if it happened yesterday) if the blurred vision would remain, I won't be able to drive my car anymore.



Unfortunately, acquiring CML wasn't the worst part but learning of sub-optimal treatment response and even treatment failure. I have struggled with uncertainty of prognosis for quite a number of years. Took "second opinions" with high-profile CML experts around the potential of a stem cell transplant. But being heavily pre-treated and growing old on CML I wasn't convinced of success with this option.

With a bit of patience I have reached MMR after 14 years of treatment. I believe well-being comes from both practicing yoga which supports strength, balance and concentration and, patient advocacy activities which are a meaningful way of directing one's energy - as an alternative in a discontinuation of a professional career.



I am not eligible for TFR (treatment-free remission) but I benefit from dose reduction and, intermittent administration 5 days on weekend off-therapy.

I can divide my life before CML, being a lonely person working in an isolated environment. When I've set up a patient support organisation, it was a major change of getting to know people, both patients, clinicians and researchers whom I would never meet before. A valuable experience.



COVID times have no impact on my CML treatment/monitoring since the clinic is the only place I could get further drug supply, so my appointments are scheduled with the same frequency. Perhaps some logistics issues because I travel to a university clinic far away from Prague.

As for vaccination, within the Patient Advisory Board of the Health Ministry we have pushed for prioritising chronic patients and, we have supported the Health Minister in vaccination plan incorporating only EMA-approved vaccines.



I start the day with online yoga zoomed from my yoga studio, followed by more zoom meetings, webinars etc. in combination with running a non stop telephone line for patients. I can look at photos from my garden which is located out of Prague where lockdown won't allow me to go. Then I can share my impression on Teams with my team members.

Inspiring CML patients

I think it's not the COVID but CML has taught me a lesson:

To wait and hope for things turning to the better.

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

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