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LIVING WITH CML

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



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My name is **Toni Montserrat**, I'm 53 years old, happily married to Ana from 1996. We have a 14-year-old daughter, Laia. My laptop joined our family until we agree on a friendly separation (:

I worked for more than 30 years in management positions at the Administration, Finance and Operations area for multinational companies and lastly, in 2012, I co-founded a startup to promote children's reading. During my entire career, I strongly dedicated my energy and fulltime to every position I have held.

In September 2015 I was diagnosed with CML, and after 3 months, my general practitioner recommended a change of pace and prescribed me a temporary leave of absence at work. As a result of this decision, in May 2016 I was "invited" to leave the project in which I left my last four years of intense work. My laptop was no longer the fourth member of the family.



When I was diagnosed with CML, I felt scared, worried about my family's future but surprisingly, not about my health. Although the messages from the haematologists were somewhat optimistic, when they called my disease as "the good leukaemia," something about that didn't sit right with me.

My doctors' instructions were, in summary, just take one pill every day, reduce my daily stress and start living in a more relaxed way.



In the last 5 years, my daily life with CML hasn't been really comfortable: I still wake up every day tired and fatigued with pains in my back, knees, hips, joints, with memory problems, a slow brain and lack of concentration as well.

I also strictly follow a daily medication-routine including my Tyrosine Kinase Inhibitor (TKI), drugs to control hypertension, cholesterol, triglycerides, diuretics, anti-inflammatories, painkillers, antidepressants, sleep relaxants, without forgetting neuropsychological training as well.

I have trained myself to accept this new rhythm of life with the help of the psycho-oncologist, trying to develop slower activities, sleeping more and napping every day for the first time in my life: in summary, better listening to my body and brain's needs.



But the main concern is no longer the medical one. After 18 months of the temporary leave, the public administration, despite all the medical reports provided, determined that I was prepared to continue my usual work in a miraculous way.

As a result of this impossible requirement, I started a personal battle against the Social Security organisms in Spain to achieve a fair recognition of my disability and health rights in the Court. The final resolution is still pending since 2018.

In fact, my legal situation is a long-term unemployed person, with a recognition of 40% of disability, entitled to a very limited monthly allowance as I am over 52 years old, living on savings and the pension plan...but 15 years earlier than expected. Financially surviving to my cancer is an extremely difficult challenge to face.

It is really hard to say what it hurts me the most: if living with side effects of my treatment, which are very similar for me under Imatinib, Dasatinib or Bosutinib drugs, or living with the uncertainty of the Court's decision and my labor precariousness due to my CML diagnosis.



Making the best of living with CML is pretty clear for me: to have met wonderful people from all over the world, either personally in the CML Horizons Conference and other advocacy meetings or even through the social media networks, who are giving unconditional support to the CML family.

Having these amazing people close to me, it is easier to feel like helping others, sharing information, being part of new projects... Thanks to them I feel I am a patient advocate today.

On the other hand, the bad side of living with CML is certainly to not being able to enjoy activities with the same energy as before, to not being able to plan ahead as I used to do before the disease.



But from my point of view, that which has been extremely harmful to me has been the contempt and inhumane treatment I have suffered as a CML patient, both by some haematologists and other doctors who were in charge of checking my physical ability to work.

I expected those doctors would understand and support very well my condition and never ignore it. Although unfortunately, for those physicians, a CML patient is a number, someone who takes pills, makes analytics about BCR/ABL levels, and that's it. They completely ignore the side effects of TKIs, your personal situation or the impact of the disease across any aspect of your life.

Therefore, finding a good haematologist who understands our condition, is up-to-date, open to listen, discuss and agree on the best course of CML management, is a real challenge to overcome and achieve well-being while living with CML.



I am currently participating in a clinical trial, including monitoring tests every 6 months, so I have not had any problems with the supply of TKI (or any other medicine) because of the COVID19 outbreak. Last May I should have had a blood test and drug collection at the hospital, but I was informed of a delay and the medication was sent to my home.

During the worse weeks of the pandemic in Spain, all the medical appointments were suspended at my hospital but some services such as the psycho-oncologist consultation were still offered but by telephone.

Personally, I used to spend quite a few hours at home every day before the global pandemic, so this new situation hasn't had a huge impact on my daily life and I have taken the golden opportunity to recover good habits such as reading books, press, scientific articles... and listening to music or watching TV as well.



Inspiring CML patients

Life is short, we are only here once, and already when we arrive at this world, we all know that one day we will leave it.

But in my opinion, the most valuable learning we have got because of the COVID19, is the unpredictable aspects of our lives: our world, the way we live, our whole life can be drastically transformed in unexpected ways.

Enjoy now, the future is not yet here.

EUPATI Fellow

Toni Montserrat

The possibility of finding comfort in an engaged network that provides support and advice has helped me to deal with my diagnosis and to continue growing as a patient advocate.

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

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