



My life with lupus... “Don’t stop me now”

I’m Claudine and I am 42 years “young”. I was born and raised in Ostend, a beautiful city on the Belgian coast. I’m married to Ralph and I’m the proud mother of Lennaert (16) and Lisa (14).

I love writing and travelling, have a passion for music, wine, study and good food. I am an optimist who enjoys the “little” things in life.

I learnt about the Edgar Stene Prize through ReumaNet, our Flemish patient association. I wanted to participate because I think that “sharing is caring”. I hope that my essay can inspire others to take back control over their lives – enjoy the little things, be grateful for the things we can do and live our lives to the fullest even with a rheumatic or musculoskeletal disease... Because we are so much more than patients.

“What did you do last night?” I ask myself as my alarm clock went off in the morning. And to clarify, I had done nothing special during that night.

But, like every morning, I wake up with the headache, the flu-like feeling and the rigidity of my body. “The usual stuff”, as I always tell my husband when he asks me how I am. But this time it felt as if I had run a marathon. Which I hadn’t.

I knew this was coming. My wolf had warned me with his subtle signals.

“You’re going too far, you are ignoring me too much,” he admonishes me with his finger in the air. And I know, I realise it. But it remains so attractive to be able to keep up with everyone. Without being stopped, without being slowed down.

“Everything happens slowly”

After a few minutes, I pull myself out of bed. Everything happens very slowly. I find it difficult to think, to move and to breathe. “I’ll have to be patient with myself today,” I mumble quietly.

In the distance I hear the voice of my son Lenny. He is waiting for me at the end of the staircase with his arms wide open. I feel so blessed. His big hug creates the first miracle today.

“A big smile appears on my face”

At our breakfast table I close my eyes while I enjoy the scent of my coffee. Hmm... this is another blissful moment. And a big smile appears on my face because the sandwiches I’m making with sprinkles will taste so good with my coffee.

My mobile beeps and, in a blink of an eye, my face brightens up. It is a text message from my daughter Lisa. She is on a school trip this week. Her message makes me laugh. I miss her terribly! I can’t wait to see her again and to close her in my arms.

In the background I hear the song “Don’t stop me now” by Queen, with the ever-inspiring Freddie Mercury. They are still one of my favourite bands. I turn up the volume of the radio because it’s a great song – it’s exciting and it makes me incredibly happy! Really, you can’t stand still on that song can you? And

the small dance movements that I'm making also do virtue to the stiffness of my body.

I sing along with the song:

"Don't stop me now..."

"I'm having such a good time, good time..."

"Uh, good time?" I think to myself. No, not really no.

However I'm singing all the air out of my lungs.

Absurd, isn't it?

You know, in my mind I'm not sick. On the contrary... In my mind I'm unstoppable.

I read once in a newspaper: "Look more to your talents and less to your limitations." That's wisely said. Often we focus too much on the things that we can't do and it inhibits us. Mostly it's our thinking that limits us.

"I feel this fire inside me"

Although my lupus is still quite active, I feel this fire inside me that can't be diminished. So I had to find something that I could do with my talents and within my limits. Something that made me feel useful again. Something that I could do at my own pace.

A couple of years ago I started writing about my invisible illness and I share it in

my blog <http://wolfandthecity.blogspot.be>. It creates more awareness and more understanding about living with arthritis, living with lupus. And the most beautiful thing about sharing these little parts of me is that I'm also helping and supporting other patients. And this still gives me a lot of warmth in my heart.

"United we are changing the world"

And that feeling of helping others through my experience as a patient gave me the impulse to do more. So I now engage myself as a patient-partner and as a patient representative. I'm so happy that I can contribute and speak up for those who are temporarily unable to. I can hardly describe in words the powerful energy when we are working together in a patient panel or at a convention, putting our hands, our thoughts and our energy together. United we are changing the world into a better place for patients with arthritis. It gives me so much mental energy and friendship in return.

There was a time when I had the tendency to postpone the things I wanted to do because of my illness. But now I just do them! So I'm learning to play the piano and I love it. It stimulates my brain again. And recently I got into yoga. It helps me to regain strength. And during drama classes I'm learning to express myself again. All this makes me feel so alive again.

"Every day I scan my limits"

You know, I am aware of my sick body. I am aware of my "limitations". Every morning I get up with my wolf fur. And every day I scan my limits. What I can do and what not. What will work today and what will not.

It is what it is...

But, besides being ill and having daily pain, I also experience very beautiful, intense moments of happiness. Even if they are only fractions, a few hours, it doesn't matter. I'm especially grateful that I experience them. My focus is on the things I can do, not on what I can't. And even though my wolf often challenges me in all my enthusiasm and, even if I follow my path with much trial and error, it will certainly not stop me following my heart and doing the things I'm passionate about. It will certainly not stop me being intensely happy too.

Don't stop me now...

You are right Freddie.

The show must go on!

That's the spirit ;-).

My blog <http://wolfandthecity.blogspot.be>



Networking during a convention

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Sharing my story for World Arthritis Day 2016