



Maria Pilar Pazos Casal
Spain



At an important presidency event



Relaxing with my husband Tino, and our dogs Bilbo and Troylo

The key to enjoying life

My name is Maria Pilar Pazos Casal and I am 54 years old. I live in Ferrol ((La Coruña), Spain. I was a teacher by profession but I am now retired due to absolute and permanent disability.

I heard the call to enter the Stene Prize competition through the Spanish Federation of Lupus (FELUPUS). I decided to participate because, ever since I was diagnosed with my illness, I knew I faced a new stage in my life. I have wanted to dedicate my life to helping others and believe that my story can be an example of that. Although it takes a lot of courage, I know that you can live with a chronic illness without losing your smile.

I have always been an “oak” without even realising it. Maybe when fate “heard” me crying for the first time, it became obvious that my life was not going to be rosy and I was given the gift of strength.

In the autumn of 1984 I discovered lupus, with its fears and anxieties, with its heart-breaking future image. I did not want to turn into a weeping willow; this strength I had inside me anchored to the life I would now begin to “live” with strong roots. My body suffered... I cried for my parents, for my love, but there was no point feeling sorry for myself, there was no point asking questions... My roots clung on and there were others helping me, holding onto my branches, caressing me with their leaves... and so I began to learn to live with my lupus.

Having a disease is hard – we all know the everyday details of that. But even if you have a disease, there is no need to feel ill. That’s the key to enjoying life,

making sure “normality” takes over everything. In the end, we are able to follow our life’s path, knowing our body, listening to our heartbeats, learning about our illness and letting life go on each morning.

La importancia del roble va mucho más allá que la utilidad de su madera... Para todos los pueblos que lo han conocido constituye un sinónimo de fuerza, de no dejarse doblegar ante ningún obstáculo. (The importance of the oak tree goes far beyond the value of its wood... For all the people who have come to know it, it is synonymous with strength, not letting oneself be defeated by any obstacle.) Miguel Herrero Uceda, El alma de los árboles

“I began to live my life”

So with that strength, I began to live my life. Living your life with a smile makes everything simpler – easier for you and for those around you. You need to start by introducing this normality to your family and your work environment, your friends and neighbours, showing them what it is like to have a chronic disease and going through it without any dramas. That would be a good start

for a somewhat rough road, where you need to learn to be patient and to love yourself. I learnt to understand others and how to make others understand me.

And life goes by, like the seasons – either freezing cold or real spring weather, falling and rising again and again... with the help of my loved ones.

I learnt to ride a bike when I was 40! I could not believe it!!! Now I have a tricycle, but I continue to “run” without losing my smile. I had two travel companions – Bilbo and Troylo, two wonderful poodles. They made me really happy and, together with my beloved Tino, my partner, my husband, my friend, we became one happy family. These are magical moments in one’s life and they mark you for life. And I was happy.

My work was always gratifying. I taught my students so much and learnt so much from them at the same time! I remember their faces in the adult education for dependents phase. Every day was a gift, every sad story was exciting at the same time and I was happy to see adults learning to read and write.

I cannot even describe how good it feels knowing that you have helped make this possible: we read, we did maths, we drew, we told each other small and big secrets, and some even fell in love. I was feeling more and more grateful for all this. I had other

students, always adults. They were complex students with various integration issues, coming from broken homes. Each year was a challenge, a desire for them to show enthusiasm, a constant struggle for them to “like themselves, for them to be convinced that they were worth a lot, that they had a future”. I was growing up with them and I was happy to see their achievements.

“I have to get a lot more rest than friends do”

I don’t have many friends but my friends are all wonderful, they are like gold. Spending an afternoon with them is like reliving my teenage years, although I must admit that after every outing I have to get a lot more rest than they do... and I go on laughing and living.

My parents... their grief over my illness, keeping it all inside so that I would hardly notice. My father is no longer with us... My mother is always there and that makes me happy. My diagnosis aged them. It aged their body and their soul. Having them around always made me happy.

Altruism, love for others, solidarity, empathy... This was a very happy phase and it taught me a lot. It was the phase that made me a better person. 1997 was a very important year. I got involved in the fight and support by and for all people with chronic diseases – lupus in particular, which is the disease I have. And yes, I do have to be grateful for this choice of life.

I have got to know so many wonderful people. Without lupus they would not have entered my life. There’s always the bright side, “Hakuna Matata”, despite the adversity, the pain, the medication, the hours spent in hospital, the cold operating rooms, the intensive care units, despite the losses... We need to live our life, enjoy it because that’s all we have. It is just one word but it is so important. If we know how to use it with empathy it can become immense.

Prioritising. This is a word I like. Prioritising is the key to living life to the fullest. Knowing how to find the formula that allows us to feel happy with our limits, sticking to what makes us happy and getting rid of everything that bothers us. It’s not easy, nobody gave us an instruction book showing us how to do it.

“Enjoying life to the full is so relative”

Enjoying life to the full is so relative. It all depends on what we are expecting, on habits such as reading and writing, drawing, listening to music, motorbike rides or walks in the forest, the sea... emotions, smells... Everything is a gift of life, trivial things that we hardly use. Without any great aspirations we can be happy, we can be made happy. At the end of the day we need to be happy with what makes us happy, letting the disease guide us.

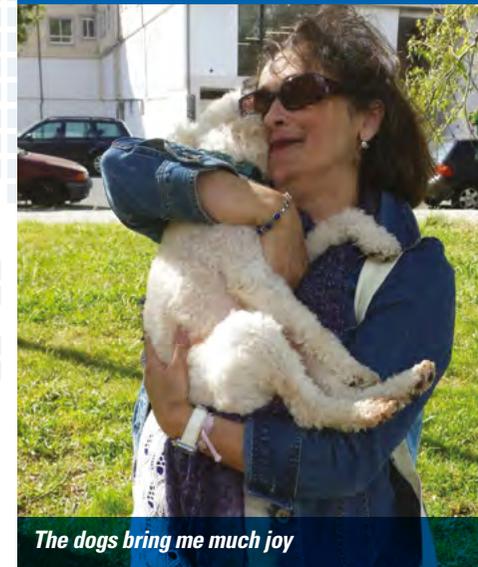
Even if we are suffering from a disease, it is the heart that should

guide our actions. We need to keep it healthy for our emotions, to be able to give and receive.

Having fun for me is giving your best self. As Voltaire would say “I have decided to be happy because it’s good for my health”. And what I like is making the most of things – enjoying every moment of my life, always with a smile, never wasting time. All of course to the extent that my body lets me do it. And I am an oak.



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The dogs bring me much joy