

Progressive Multifocal Leukoencephalopathy (PML) - November 2nd, 2010.

The first question I will ask you as I attempt to write my thoughts for the day is "Is this rare brain infection a sentence to die???" This what you read on the internet. They give you 4 months to live and no sign of hope. If you're looking for hope, you better find it yourself.

There are moments when I feel like I am on death row. These moments are then mixed with beautiful images of my homeland, of the places I love, images and memories of the true friends that I have had for 25-30 years and that have been through everything with me.

I feel like everyone is playing and betting on my life! I never played roulette but something tells me that what I am feeling might be what a gambler feels at the table. You don't know when the little ball will stop spinning and you don't know where it will land. While I write this letter with one finger, ONCE AGAIN, I simply wonder WHY... I have been through this before. I lost the use of my left hand twice before and I worked hard and I was lucky enough to get everything back both times. Now I ask God: weren't those two times enough to teach me not to give up?? Did I forget to learn something at those times and there is something else that I still haven't seen and learned??? While I write this, I get more and more frustrated because my thoughts are running faster than my fingers can type and I am afraid I won't have time and energy to finish writing this letter...

I always believed that everything that happens to us will be useful and it will teach us something new. But I do wonder if I proved to be too stubborn with this too: didn't I learn to be patient and wait for better times the other times when I lost the use of the left side of my body: did I forget to learn something and I am in this situation again because I missed paying attention to something before??? While now I see blurry, at those times maybe my vision problems were inside my heart and, maybe, I couldn't see what God wanted me to see and now I am back in the same/or worse situation because of me "missing the point" before!

The question I have at this point is: how many times can the body heal itself? How many times can someone want to learn how to write in the course of their life time? Shouldn't 4 times be enough in the only 37 years? I can assure you that 4 times is more than enough!!!!!! I did enjoy school a lot (ask my true friends) and I loved learning to write and working on my penmanship (my calligraphy is considered pretty good in my country and not so much in the States)... I wish I could find a way to make people understand that the two cultures are very, different and so are the two worlds that I lived in during my life.

Nothing comes easy and nothing comes natural any more: I force myself to walk, to drink, to eat(well, I am Italian and the appetite will be the last thing that will go....!!!)☺

Everything I do throughout the day is forced and nothing comes naturally. I have to think before doing any of the things that are part of our normal, daily life. Something like swallowing, is a full time job, it's not just a normal reflex. I have to think about it and imagine the steps in my mind before I let it happen. These are the moments when I realize how amazing our bodies are and how everything we take for granted is a lot more complicated than we think. It takes a lot to swallow something and I learned that swallowing solids is a lot easier than swallowing fluids. I am not sure why (but I am sure I will learn that very soon).

I started worrying about my fluid intake during the past two weeks because I went from drinking 2 liters of water a day to just one or two glasses. I knew that I had to make a change and I had to force myself to drink more, so I am making myself to do this too. The left side of my mouth is a little weak and this has caused some problems chewing and speaking, and sometimes food or fluids may come out of my mouth, but Keith says my kissing is still pretty good. I haven't had a problem eating yet (the story of my life!) and my appetite seems to be pretty good (it's getting challenging eating American food more and more, but if it didn't kill me before, I think I can make it through).

Mobility wise, I am still doing very well. Every evening, after my husband is done with work, we go for a walk around the park not far from our house. The only difference I see is that my left foot is not raising as well as my right foot. There are no changes in me going up and down the stairs or in taking care of myself. This is the part where I feel like a bomb ready to explode. I look and feel pretty good, except for my mouth being a little crooked and lazy. But, I am puzzled. If I look and feel pretty good, how can this virus be doing so much damage in my brain?

Now bear with me as I ask you some questions. They may sound funny to you but I do have these questions and I would like to write them down and share them with you. Hopefully they will make you smile...lately I am wondering how people will remember me and I don't want them to remember me in a sad way, so if I can make you smile with my silly questions, I will be pretty happy. The first question is: Do cute doctors have an easier way getting into medical school? How is it that most doctors in the states are very good looking? Why, when neurologists perform an assessment, they don't suggest that you kiss your loved one to make sure your mouth and facial muscles are working properly? Don't they have any creativity? Why don't they just make things simple and straightforward?

These are some of the thoughts that I was having during my stay at Hopkins when I was walking around the floor of my hospital room. I did have music in my ears, but my mind was working overtime and I was thinking about millions of thoughts at the same time. This never changed. My mind seems to still be able to handle a lot. Not everything makes sense, but most of it still does. I went from listening to music to having very confused thoughts about my past to wondering about my future. I ask myself why I can't remember certain things while I can remember others. In the hospital, there were two times when I completely drew a blank and couldn't remember what was going on.

Another little mystery that I am trying to figure out, has to do with the position of my head. Keith noticed that after the central line was removed from my neck, I started tilting my head towards the left, probably because I had the line in the right side of my neck and had been pushing away from it for over a week. When I tilt my head to the left, I feel fine and am balanced and see OK, but when I tilt to the right, I have balance problems when I walk, I don't feel good at all, it just doesn't feel right, and the left side of my mouth starts salivating. If I tilt my head from the left to the right too quickly, I have a sense of vertigo and nausea and sometimes some electrical shocks. As you can tell, the questions and the mysteries are many. I don't know why these things happen. I don't know why I can go from laughing hysterically to crying in just a matter of moments. The only thing I know is that I don't like how I am feeling and who I have become in such a short time. I can definitely say I don't like PML!