

When the fight begins, it's like you're knocked out instantly. After long weeks of doubts, the diagnosis feels like an uppercut. And often when you're KO, you have no idea what's going on, you're stunned. Our universe as we knew it is now gone. But that's not all, because this KO is contagious and anyone who loves us is stunned and confused as well.

This state can last several months, or even years. It can also never stop. Worst case scenario, death can happen few months after, which will knockout your loved ones once again. But my point is, no matter how long you will never feel completely conscious. Not when making decisions, and neither when trying to get people to listen.

A ton of new elements will also prevent you from regaining full consciousness. First of those is anger, powered by the feeling of injustice and the all too well-known "Why me?".

I've already spoken about these feelings and the horde of negativity they bring with them.

"That Bitch of a Disease!" We can't hate it, it's part of us and it's not going anywhere.

Instead, let's try and see the world we can rebuild with it, because of it.

But also, can we make our voice, our cause, acknowledged? 'Cause they listen too little, and we're too busy doing other things like: survivin'! And the short time we have left is dedicated to rebuilding your life with your family.

So who is speaking for us?

And what are they saying?

Numerous associations with admirable people are here to help but are we truly acknowledged?

Is research going as fast as it should?

Are budgets big enough?

Are we being treated with dignity?

Let's call a spade a spade, I usually felt like it was "Hide away that tetraplegic before my eyes" more than "How can I help you?". And we just accept it, we die in silence, we disappear, we don't want to be a burden. We even chose a butterfly as a symbol. What's more fragile and ephemeral than a butterfly? I mean sure it's beautiful and poetic but it also

says a lot about our state of mind; we accept to be ephemeral, how beautiful. Meanwhile we quietly die, and the newly diagnosed don't have more chances, more time to live than in the last century.

I obviously have all the respect for the founders of this butterfly concept and I think they had good intentions but I'm not a butterfly, — *I'm a tiger*. A tracheotomized and fed through gastrostomy tiger but a tiger still, and I refuse to fade away in silence. I don't hold any anger and I'm happy and at peace but I will do everything for us to stop quietly dying in the corner.

First of all I find it scandalous that the majority of the medical community, neurologist at the top, sentence us without even talking about tracheotomy as a solution. It's certain that if all of a sudden, thousands of patients decided to live with the disease for as long as medicine allows them, it'll cost a fortune to public authorities and they'll look more into founding research facilities. To illustrate what I'm saying, I'm in contact with molecular biologists working on fundamental research at the C.N.R.S. [i.e.: the largest governmental research organisation in France] in Strasbourg. The team is the reason behind the spectacular progress made this year. They're in collaboration with Harvard University for clinical trials. By exchanging electronic mails with the research director, I learned he wasn't sure of going through with the researches because of lack of foundings. So I asked him how much did they need. He told me he could keep the team going for 2 years with 28,000€! I was shocked. I'm not naive, I know that money don't grow for the research itself (*les vases ne communiquent pas*) but it's the same cost as 2 months of home care, or one week in intensive care. This number gave me vertigo and outraged me at the same time.

Peccadillos, this is what our government gives us. And we accept it, poor little butterflies.

But it's not just about big ol' money, it's also about ethics, about mentality. Wanting to live without our muscles is often perceived as a use of intensive medication, nonsense. Yet we still have what makes us men and women, and what differentiates us from animals, our heart, our head and most importantly our soul. Are we abominations without our muscles? So where's the nonsense? In what they want us to believe or in this philosophical and physiological truth? *I personally refuse this metaphor of the butterfly that is being freed once it dies.*

It makes us think it's the only way to find peace, which is wrong and an awful picture to paint to new ill people.

With that picture in mind, we start out the underdog, when all we need is hope.

I'm the living proof that hope is not pointless, I'm ill and happy.

So roar little butterfly, roar.

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