

I received again this morning an email about someone who lost their mum due to sudden ALS, and who told me that if they had been better informed, things could have been different.

I'll say it again, *with an appropriate respiratory assistance, the disease can't kill us right away*. More so let's be clear, it's not like we're becoming immortals, and "peripheral" complications sure can happen, but the main reason of death, a.k.a. respiratory arrest, is avoided. Which can allow us to live for another ten years and more, if you accept to live with respiratory help for an undetermined period of time.

The lack of information on the topic is tragic. Many families grieve before realising there was an actual solution.

So why is there so little information about it?

First of all, there is a major part of the medical community that consider living with a respiratory assistance to be some kind of therapeutic obstinacy, because of how long and aggressive it can be. So most of them are against it.

They will easily talk to you about N.I.V. (non-invasive ventilation) but less often about tracheotomy, or at least not in a good light. Unfortunately, it's the only option if you want to survive longer than the "official" life expectancy.

It's necessary that every patient knows all the facts before making the most important decision of their life. So you need to write your advance healthcare directives, knowingly and without being influenced by doctors. Personally, the only opinions I listen to when I make a choice are the people that I love and love me back.

Here's an example of medical staff actively being against tracheotomy

Even after I specifically said in my advance directives that I wanted to live by any means necessary; when I was admitted to intensive care, after my respiratory arrest, my survival was still debated. If my wife hadn't been here to make sure my wishes were respected, I don't know what would have become of me.

However, once they got the message and the staff understood our project and saw how determined we were, they did everything they could to help me and turned out to be incredible caregivers.

Since then, I'm fighting so that tracheotomy is presented as an actual option instead of a

slippery road doctors don't like to take when talking about solutions.

I don't know if it's about personal beliefs or dark hierarchical commands though. It's true that a tracheostomized patient costs more than a dead one. I don't wanna seem rude, but the question needs to be asked, the main preoccupation of a doctor being the life of their patient.

Anyhow, I need to send my regards to the large majority of caregivers I have the chance to meet, who happen to be amazing. I thank all of you.

To conclude, inform yourself and don't take *the* decision without knowing anything.

I wish you to be strong, it's what your loved ones expect from you, whatever choice you make...

Kisses to y'all, everything's gonna be okay.

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