

Here we are, the taboo subject.

Taboo for patients, but for the medical profession as well. Most doctors think that long-term tracheostomy is a form of futile medical care, or therapeutic obstinacy. Sorry for wanting to live!

And taboo for us, because it is what marks the border between life and death, let's call a spade a spade. ALS's deadly plan is to stop our ability to breathe by paralysing our respiratory muscles.

Sorry for being so direct. We mainly die from respiratory arrest. I did mine, and thanks to my advance directives in which I stipulated that I wanted to live by all means. It still costed me 2 months in intensive care. I won't go through all the details, but if I'm telling you this, it's to tell you one more time to not do the same mistakes as me. So **AN-TI-CI-PATE**.

If you choose to live, some might say: Okay, but, what kind of life? Today, the only struggle that I'm fighting is this one: yes, a happy life is possible, because once your tracheostomy is set up, so long the stress from death's grip: fuck death!

If you choose to live, as I was saying, you need to anticipate that procedure. If breathing gets more difficult despite **N.I.V.** (non-invasive ventilation) or if pulmonary aspiration is becoming a real danger, it is time to ask about it to your doctors (neurologist, pneumologist, GP...)

So what does it mean exactly? Basically, your air supply goes through a tube inserted on your throat. Quite unattractive, but painless, it is the price of life. You are not only ventilated (by a ventilator: I will expand on that in another article), but you are protected from pulmonary aspiration by a balloon that obstructs your trachea to only let air through.

ALS is now contained.

A hospital ENT will normally perform this medical act. It is quite simple. However, tracheostomy care is a whole different story. Whether you are in home-based care or a doctor's office, you will have to train them, except if one of them is a former intensive care practitioner. Yet, none of this is insurmountable. My wife trained everybody, caregivers and nurses included. She was trained in intensive care during my stay and today is on par with an intensive care nurse when it comes to my disease.

Every person that could ever be alone with you must be trained, and you must not stay alone, in particular for tracheal suction and possible ventilator issues. But stay reassured:

once you are well equipped, technical issues are extremely seldom.

So, forget solitude. The best option is to get the person who lives with you (if there's one) to be trained in everything. This avoids the presence of a caregiver 24/7, which is not the best option for privacy.

The big downside to tracheostomy is the monthly cannula change, to prevent adhesions and possible balloon porosity. Once again, it's a simple procedure, but it requires the presence of a specialized doctor. Or else, you will have to go to the hospital every month to make that change. And then, it can get complicated: it was for me.

The first hospital ENT who made that change forgot to reinflate the balloon, which is not super serious but proves he wasn't used to this (despite the fact that he was one year away from retirement) and it's my wife, seeing the mess he made, who inflated it. Worse than that, he advised us to do a yearly change from now on, which is basically reckless.

The second ENT who tried just put the new and sterile cannula on the emergency unit's bench before setting it up on me. It costed me a two months fever because of a staphylococcus aureus and a pseudomonas. Those bugs love tracheostomy. But nothing serious.

Then I decided to switch hospitals and get to a hyper specialized ENT. And then when I realized this "specialist" had never seen a closed-loop suction system, I was flabbergasted. Ah, yeah, you have to demand a closed-loop suction system: way simpler to use and it reduces septic risks down to 0. It also allows a more efficient evacuation of tracheal secretions.

The point of this story is: true specialists are hard to find. Hospital ENT don't see enough tracheostomies, emergency doctors are more used to setting them up in an emergency when they can't intubate. The true specialists, for the set up, changes and follow-up, are *resuscitators*. They see tracheostomies all day long. But you can't get admitted in intensive care for a cannula change.

Then what should be done?

We should create a new medical specialization. Oh, wait, a little bird just told me that this speciality already exists in Canada, under the name "respiratory therapist". They're skilled in everything that covers care of respiratory tracts. (Tracheostomies, N.I.V.s, suction, oxygen, chest physical therapy, aerosols...). So what are we waiting for to import this particularly appropriate idea?

Meanwhile, you absolutely must find a doctor who will accept to take the responsibility to perform this procedure in your house, and that's not a piece of cake. Being tracheostomized and ventilated at home means you're a big league player. As a matter of fact, I'm the only one in my region in this case.

It's a matter of responsibility. This procedure can be done by a skilled nurse, but a doctor has to overview the operation. And the general practitioner around the corner will not take this responsibility. Most of the time, you're their only patient with ALS and they've only seen tracheostomies inside books in college. You will have to find a true gem. For me, a senior emergency doctor comes to my place every month with an intensive care nurse. As a matter of fact, they just left and everything went great, as usual. I have to say he's a very prominent doctor, of Senegalese descent and also very young, which might explain his lack of unwillingness compared to others of his peers that I have solicited.

I can sometimes seem harsh towards the medical profession, but I think this situation is endured rather than wanted. Anyway I've met too many fabulously amazing professionals to allow myself to criticize them unfairly, I'm just trying to make a difference, in my own small way.

So, now you are tracheostomized. Note that it's very rare, in medical care, to keep this kind of apparatus on the long run. It is mainly used for ENT cancers, or when resuscitators or emergency specialists cannot intubate a patient. Hopefully, it is removed after a short while in most cases.

But for us, it's different. We kind of revolutionized the world of tracheostomies, we use them to live for a long while. Therefore, a new market has spawn, with dozens of cannula types, way much more comfortable and convenient than basic models used in intensive care.

Foam balloons allowing to swallow, valves and cannulas allowing speech, all-extra flexible silicone designs... If this keeps up, they are going to invent connected cannulas!

All that to say, you aren't condemned to keep the first cannula that was set up on you. You can make salesmen come to your home and let them present their wares to you, you are a big client from now on.

Well, I think I kept you here long enough for today. I tried to be comprehensible without getting into too much details.

I will get back to living with a tracheostomy and risks in further articles, and you will see that many falsehoods travel on that topic, which is even more serious than lack of

information.

Partager l'article !

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