

ALS patients' follow-ups at the Regional ALS Center are way too irregular.

Appointments can sometimes be 6 months apart. They are probably doing the best they can but it's just not enough to check on the weight and diet of deinstitutionalized patients.

Your GP/family doctor could do the job but... Firstly, they are not necessarily trained for that; secondly, they might be overwhelmed; and lastly, they can assume the center is taking care of everything.

Consequently *you are the one who has to be aware of it*. Don't make my mistakes, folks; I'm 5'8/1,77m and when I got taken to intensive care after my respiratory arrest, I weighed 101 lbs/.

I was a case of advanced undernourishment, which could've cost me my life. Intensivists were doubtful about my fate because I got serious complications — that don't need describing — because of it. Yet a year later I gained 55 pounds and they were shocked. All thanks to gastrostomy.

I know many of us made another choice, and I respect it; I actually discussed it a lot with Anne Bert — rest in peace — before she left for her last trip in Belgium. She couldn't picture a life without her muscles. I hoped until the last moment she'd change her mind but she was too determined, it was a "normal" life or nothing. I cried. Anyway, for those who chose to go for the adventure, and I don't say it enough but an island of peace and quiet can be found behind the hurricane, I strongly recommend you check on your weight. Between the eventual swallowing troubles, loss of appetite and bouts of depression, it all goes very quickly.

Once again, I'm no doctor but my advice is: beyond a loss of 20% of your weight → gastrostomy. For those who don't know, or don't wish to know (like I used to), it basically brings the food directly into your digestive system. Under anaesthesia, they pierce a little hole (few millimeters) in your belly to insert a flexible tube, and that's it. You won't feel anything, before or after.

Time for the feast...

It doesn't stop you from eating or drinking normally, but it guarantees you the good nutrients you need everyday — and that my friends, is pretty awesome because you're gonna need a lot of strength.

Many patients, equipped with that device, found the joy of having meals again, which could

previously take hours to finish, not even mentioning what happened if you swallowed wrong and the infectious pulmonary consequences this could have.

An infusion pump will be installed in your home and it'll push the food - which is inside a pocket - through the tube and into your digestive system. A district nurse is competent enough to handle it all. Of course, hydration can move through it too and anything liquid really.

I personally put honey, pollen, and all kinds of food supplement **[link for the text "A drop of honey"]**.

Treatments can be administered with it, so enough with saying it's useless.

You need to see the bright side of things... There's no high maintenance needed except for rinsing the tube after each use to prevent it from clogging up.

It seems like bubbly water is the most efficient. In case of obstruction, use an acid soda or hot water to purge it. If it's not enough you'll have to drain the feeding tube where the obstruction is, thus as to remove it.

Depending on the tube, it'll need to be changed every 6 to 12 months. It must be done at home by a qualified nurse. It's very quick and painless.

There's, no need to be hesitant to do it now. In the end, it's pretty much nothing. *The keys are anticipation, and also contentment.*

We all had amazing lives, more or less, and now, we just need to be satisfied with what we got. To see the glass half-full, even if there's only a drop at the bottom.

After a year of gastrostomy

Partager l'article !

Leave a comment with your Facebook account