

Throughout all of a patient's life, and no matter the stage of the disease, you must be accompanied by a pluridisciplinary, competent and active medical team. France's ALS centers aren't available enough to accommodate all patients. Just look at the time to get an appointment or how spaced out are the follow-through appointments. Chances are it's the same where you live.

They might be very competent, but they are far removed from our daily lives.

The one who is closer to us is our primary care physician. But, no offense to them, they are often left behind concerning our disease, and you probably are their only case. Plus, chances are they're uncomfortable with care because the psychological support of patients affected with serious disorders ain't a part of their curriculum.

However, we need to be closely monitored.

So what should you do?

- ***Learn to listen to your body***

Without being hypochondriac, we must learn to decipher the messages our body sends us. I'm talking about unusual things, such as sudden confusion, an extended headache, or different sound perception. That kind of strange sensations must be the subject of a medical appointment if they persist.

- ***Monitor your vital signs***

Monitoring your vitals means to assess your 4 primary vital signs: *pulse, blood pressure, body temperature and blood oxygen saturation* [[link for "Vital signs" here](#)]. They are very simple to take, non invasive, and that can be measured by anybody as long as they can read a manual. However, the interpretation of this data must be done by a trained practitioner, or a nurse or a doctor. What must be your reason of concern is a sudden variation of this data.

Please understand that a good oxygen saturation is not necessarily a sign of good gas exchanges. But if it drops, it means that a major issue is going on and that doctors must be notified without delay.

The apparatus that is necessary to monitor this data is very affordable and easy to find.

So get it.

- **The link**

Your primary care physician must actively make the link between you and specialists. They must smooth out all proceedings. They are the pinnacle of the whole machinery. If you have the feeling they're dragging their feet, because they disagree with your way of living the disease or for any other reason - **CHANGE**. Shop around for general practitioners around your area by presenting your case, and find out that one-in-a-hundred gem. *They must be involved.*

However, the link between you and other doctors is first ensured by the nurses that you see everyday. They will be the ones to warn your primary care physician if they have the feeling something is not right. That's why you must build a relationship based around mutual trust and understanding with them. They can also provide solid advice for many little issues, skin problems for example.

- **A dream team**

Your primary care physician, nurses, a pneumologist, a neurologist, and nutritionist, a physiologist, and at best a resuscitation specialist for advice on matters related to respirators and tracheostomies (for multi-resistant pathogens in particular), must be part of this team. An ENT specialist who is specialised in tracheostomies can be of great help as well.

With that dream team, you'll be at peace.

Note that organisms specialised in support, including medical, who are very qualified and able to help you constitute that team.

Note as well that care depends on the stage of your disease and your choices.

We can divide two periods: *pre-tracheostomy* and *post-tracheostomy*. Those 2 phases require different kinds of care, as much as in the approach than in the people that will be needed. Without delving into too many details, let's say that the first is about *active monitoring*, and the second *careful following*.

Have a good day y'all!

PS: A good pharmacist and a good medical provider should be part of the team as well. They can deliver at your place. The necessary quantity of equipment can be quite massive, so make some room.

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