

In a typical evolution of the disease, respiratory failure comes after a few years; a few months for the fast-progressing cases. We then need to resort to technical help, with the same kind of devices that are used for sleep apnea.

It is a respirator connected to a mask tightly fitted to the face which allows proper lung functioning.

ALS attacking voluntary muscles, respiratory muscles aren't spared. Mechanical deficit must then be compensated by a device.

As I didn't go through N.I.V., I can't tell you about my personal experience on that matter. But this technique that covers most of the face leaves me quite puzzled about the way it's experienced. I wonder about its psychological impact on the patient, as well as their loved ones.

One of its recurring problems is the discomfort caused by this mask, especially if it's worn permanently. We can even witness, in some cases, the appearance of lesions, around the nose area in particular. Dressings can help with this discomfort, but it seems that the protective powders used for gastrostomies are the most efficient solutions, especially when lesions appear. Some other mask-related inconveniences can appear as well: leaks, rashes, beard-related issues...

Two parameters are to be closely followed when under N.I.V. Oxygen saturation, controlled by an oximeter, and blood gas, controlled with a blood sampling from the wrist. When one of these parameters drops, it means that N.I.V.'s limits are reached.

You now have to make a crucial choice: tracheostomy or respiratory arrest.

Allow me to make a personal remark. As N.I.V. is temporary and isn't a fully efficient and comfortable solution, besides being psychologically problematic, why not go straight to tracheostomy? Far more durable and efficient, and way more comfortable once a few weeks of adaptation have passed.

I suggest you have a look at the article about tracheostomy. It's very far from being as terrible as what most specialists say.

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