

Folks, I know some of you won't like it, but one of the keys to deal with your illness in the best possible way is anticipation. I say it's unpleasant because often, patients are subject to a form of denial. Fear makes us more likely to ignore what's coming. If, furthermore, we are in a stage of cold anger with unproductive questions such as "why me?", we only feed ALS. I know it's a pain! Yet, in a not so distant future, there's a good chance that patients will face serious difficulties to express themselves, especially in bulbar onset forms of the disease. It's problematic to communicate our needs, but especially bad for the morale.

Therefore, you need to *anticipate*.

Uncle Hawking left us a wonderful gift: eye tracking. Basically, it's a small interface that we set up under a computer screen that analyzes our eyes' movements to drive it. Our eyes become the mouse - it's amazing!

We access every functionality of the computer this way, including Internet of course. That's how I communicate with you, how I listen to music, how I do my projects, how I watch soccer - *Allez l'OM!* - and so on... But our celebrated Uncle H - don't forget he lived for over 50 years **with ALS** - didn't leave us only that : he also left us vocal synthesis. We write, and the computer talks for us. With a human voice - yours if you anticipate enough. That's how I tell bedtime stories to my daughters, how I laugh with my wife, how I talk to my loved ones, and so on...

Without these amazing tools, I would be cut off from the world; the world I love and I'm a part of. I live through a machine, I breathe through a machine, and so what? I still have what matters: my head and my heart. Muscles are secondary. I'm happy and my family is happy too; nothing else matters. Without this technology, we'd all be in a cold and dense fog that I know far too well, and I will never go back to that. Ever.

All of this technology has a cost, but fortunately, organizations lend without any time limit or condition those equipments and the software that goes with them. You only have to pay for the computer, and some institutions can help you pay for it. Home lessons will be planned so that you can be at ease with a system that will confuse you during your first tries.

Don't wait to get equipped, it's way more easy to get used to it when you still speak or can still use your hands.

Every challenge has a solution.

Partager l'article !

**Leave a comment with your Facebook account**