

As you may know, I am bedridden and wired 24/7. I observed that some of you have been asking what my days look like, maybe to get an idea of what their lives could be, once they will have undertaken tracheotomy.

I always try to stay as factual and as neutral as possible. I am terrified that somebody would tell me one day, "You told me it was cool, but I'm in a living hell". That is why I don't make generalizations. However, judging from the feedback I receive, it seems that life is rather possible under these conditions. For me at least, I am very happy with the choice I've made and I rather enjoy my new life.

Now, let's describe a typical day in my life.

I wake up between 8 and 10 AM. I have two daughters aged 7 and 10 and, as in any other family, we follow the school's rhythm, and sleep on holidays.

One of my carers comes when I wake up. We begin by cleaning my eyes with boric acid and cornflower water. Next comes teeth brushing and mouth care with bicarbonate and lemon. Oral hygiene is tantamount.

Meanwhile, my wife plugs in feeding and hydration via gastrostomy.

Some people "eat and drink" while sleeping, but I am not fond of this.

First because it's not really natural, and especially because in case of an issue such as throwing up happens, everybody's better be awake.

As for me, meanwhile, I answer my emails and play chess online, then I plan my workday.

Around 11 AM (except on weekends), my physiotherapist comes for a half-hour session. Then another carer comes to help the nurse who washes me (around 12 PM).

Around 2 PM, I'm alone with my wife and we talk or I work. I always try to have something in the making. As I write these lines, I have 7 projects, all quite important.

It is also time for friendly visits, that are quite seldom as I am quite geographically remote from my friends, but some dedicated friends come quite often and it's always a pleasure.

Shortly before 4 PM, another carer comes to allow my wife to fetch our daughters from school. She stays until 8 PM and helps the nurse for the evening grooming, around 7 PM.

Meanwhile, I work. Well, it's not really work since I love what I'm doing.

The carer massages me head to toe or does some cleaning.

I am lucky to have a big bedroom that became a living room, so everybody eats dinner there.

Next, we watch TV a bit, we spend family time like we used to before I fell ill. I must say that everybody now acts normal. It took a while, but we did it. My wife rolls her bed next to mine and we sleep together like two lovebirds.

I spend a bit of time on the Internet and fall asleep between 12 AM and 1 AM, I've always been a night owl.

Here's for my typical day.

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