

My life before the lockdown :

My sister, who has a son, runs her bookstore and is a teacher, and I started 11 months ago, Echos & Ricochets, an association working on inclusion. We made the choice to live together, we see each other some mornings and every evening after work. I work, for the association, from home, except when I have meetings. The accessibility of places has always been a real issue for me, professionally, therefore I had to create an accessible job for me, with the implication and help from my sister, and the support of a close friend.

I usually have three nurses coming for the every day care. They take turns.

I am able to spend the days alone, because the Personal Assistant comes by, every weekday for an hour, sometimes more, to assist me on various things like : folding the laundry, doing the dishes, tidying, cleaning...

In Belgium, every people with a disability don't have a Personal Assistant. And in Brussels, for the French part of the population with disabilities who have PA, first they pay for the services, then, they ask for a refund at the association which provides the budget received from the State. So, people needing assistance have to have enough means to pay first. During this lockdown, many great services have emerged, but again, having enough means is essential and we know that people with disabilities tend to lack means, because of many factors such as not having a job because of the lack of accessibility.

Since the lockdown :

1. One of the nurses has been exposed to the virus, she is not coming (since 19th of March, until the 9th of April at least).
 - a. Two of them are taking turns for my care, they are busier than before and they have to include me in their schedule for the days that the other nurse would have worked.
 - b. Sometimes they cannot include me in their schedule. Fortunately, my sister and I live together. She is able to help me in these days.
2. I usually have a personal assistance service coming to ease our lives, by doing what I would do in our household if I could walk. It had to be canceled because she was coming from a company that interrupted the service for this period of the lockdown.
3. I had to interrupt the physiotherapy sessions, because my nurse had been in contact with the virus, to avoid exposing the therapist, and his patients.
 - a. My sister is helping me with some exercices.

My sister has to take care of everything now: washing the laundry, folding, cleaning our place, washing the dishes, grocery shopping, cooking. She has to include my care in her tasks, when the nurses don't come, in addition to taking care of my nephew, her son.

It is a lot to deal with for one person, physically and psychologically.

As you can see without my sister, I would not do much. What if we were not living together? Or if we did not get along? Our state does not automatically provide PA for people with disabilities. That is a problem, in general. But for situations like the one we are currently living, that should be the case. I am lucky to have her help. There are people out there going through this lockdown with their disability, without enough means to have the proper assistance and without any help from family or friends. There are people struggling alone.

One more thing, we are currently working on the fundraising "Reconnecting the Circle", we launched it last month, before the lockdown, for a woman of over 65 who suddenly became disabled. This periode we are going through is slowing it down but, that would be great if people can donate, so we can ease her life by making her house accessible. As we know, the risk of poverty in the EU is significantly higher for disabled people than for people without disabilities – 21.1% of disabled people face that risk, compared to 14.9% of people without disabilities (Hauben et al., 2012).

Let's break the cycle of poverty together.