Table of contents

Preface

What is striking in Clotilde Aubet's autobiographical testimony is that she does not fight against but with her disability.

In fact, it's a daily obstacle course that she tames in her wheelchair. "Moving around in a wheelchair in Paris is above all a real slalom between obstacles", she writes, but you have to follow her to understand these mysterious routes. When reading, we understand that the city still has a long way to go in terms of accessibility. And not just the accessibility of pavements, street furniture and buildings, but also the opening of eyes and mentalities. Clotilde decided to leave her confinement behind and her encounters with the passers-by are most interesting for the reader.

Take the bus, the lift, go on the pavement, and with her to a restaurant, a bar, a cafe, a library to understand the life of a young Parisian without prejudices. Clotilde tells you about the busy people who live in their bubble, with a phone in their hands, who do not pay attention to her. And what if these people were precisely the decision makers, the managers, the officials, too in a rush to take an interest in those who move in a different way, in a wheelchair or with a cane? Clotilde does not just testify; she confronts us with another way of seeing Paris and Parisians…

Prefect Jean-Christophe Parisot de Bayard

A for…

Acceptance

The acceptance of a chronic disease, which arrived suddenly, and all its upheavals. An acceptance needed to keep going on and live. An acceptance, but not a relinquishment.

Indeed, when you have a chronic disease, at some point you need to mourn what was before, what used to be possible, but is no longer feasible. It is not always easy, and not all sick people are willing to do it. I suppose it has been easier for me, as I only suffer from a non-fatal chronic disease. To mourn the life from before seemed a necessary step to accept the illness and to live with it. A first step to choosing life. The life that was still there, the life that remained, despite the symptoms, the limitations and the frustrations. Not acknowledging the latter would have been lying to myself and probably risking even greater disappointments. How many times did I wish that everything were over as I woke up in the morning? A short-lived hope, which always disappeared in the wake of my daily physiotherapy exercises, during which I intensely felt the burden of the exertion…

An illness is not a matter of will. And that is what you have to accept. At some point, you have to accept that feeling better is not dependent upon your good will, but that the illness is a fact that needs to be integrated into your life. At the same time, acceptance is not enough, because it seems too close to resignation. One is not condemned to doing nothing because of an illness or a disability. It is not the case nor should it be. Living with an illness is an ever-renewed choice. It means learning to appreciate what remains possible, to taste the moments of improvement and to live one's life, despite the illness.

Nevertheless, it remains a purely personal choice, a choice that every person facing such hardship is confronted with, and I would never allow myself to judge a person who decided to react otherwise. Indeed, an illness is a radical change. What I cannot bear, however, are people who are not sick themselves, and yet believe that they know better than me how I should live with a chronic disease. One day during the fifth year of my studies, a guest at my landlady's place in Switzerland, a balding man in his sixties, quite sure of himself, was kindly asking some questions about my illness.

Suddenly, he said, "Yes, with such diseases, one can only go on. Anyway, one has to do it."

Embarrassed, I chose to remain silent. How could I explain the reality of the illness to someone who thought he knew it, but did not really understand what it meant? Going on is not the only option. Each and every person has to decide freely and independently whether to fight and to keep on living. And no one, absolutely no one, has the right to tell a sick person how they should react to their own illness. Some make the decision to fight, others relent. And even if you decide to keep going, it is not always easy to do so. There are days where you simply do not want to go on anymore, days when the illness becomes too hard to be tolerated. However, on these days, I think again about this life of mine that is still there, despite the illness. I know that, once again, I will get up and choose to continue living. And I will not relent.

Accessibility

"Yes, it is accessible with a wheelchair", was the answer I received, when I bothered calling and making sure it was the case.