Learning how to live (Endometriosis – 3)

At the age of 28 I had a mind full of dreams. I was in a deeply happy relationship with a perfectly stable life. The next step came naturally: we were already a family of two, but wanted to make it grow and consolidate. With the peace of mind that usually characterized our way of being, we entered this stage of our lives prepared for everything, so we thought. Two years later, with many pregnancy tests, some menstrual delays (creating hope that painfully and easily faded away) and a simple surgery to remove an endometrial polyp along the way, we enrolled in the fertility service of a public hospital. In the first doctor's appointment, I heard the word "endometriosis" for the first time, only nine months after the alleged "simple" surgery. Despite the correct diagnosis, the doctor sent me to another hospital and told me I would have to undergo another surgery, but it was going to be complicated and risky, as it could compromise my bowel. Just like that. No more and no less.

At the other hospital, they didn't really do anything: no ultrasound or a simple exam, not even when I had to go to the emergency service with the feeling that all my pelvic organs were squirming inside me. The doctors confirmed the diagnosis of endometriosis as something irreversible, that I would have to know how to deal with, because there was nothing they could do. Meanwhile, I got worse every day. The pain and the bleeding that took my strength, my energy, my ability to lead a normal life and my smile away were getting increasingly stronger, to the point of being intolerable. At first, I thought the pain was normal: I just had to endure it, that was part of being a woman. After that, I believed it was the consequence of the polyps and that everything would be fine after the surgery. It turns out it was much more than that, but nobody wanted to stop and explain it to me.

Everything I know today about endometriosis was learnt in Internet forums, through the groups of women that also suffer from this disease, and also from the long and complex scientific texts that I read. And then I realized that everything that I had always accepted as normal – the incapacitating pain, the sleepless nights, full of both painkillers and tears, the abnormal flow that didn't allow me to go out, to get up, to react, the dysmenorrhea, the dyspareunia, the tiredness, my head always rolling – was anything BUT normal.

Society formats us in such a way that we don't realize the imminent danger we live in. We just let go, take pills and pray that pain will go away as quickly as possible. And we let this disease grow, stealing our hope, happiness, smile, and so much more.

Two years went by and nothing was done, until I met an experienced doctor who knows the disease and its dangers. “You have a serious tumor and you must undergo surgery as soon as possible” said the doctor, with a caring voice. He told my husband: “The pain that this girl has been bearing is beyond everything that we can imagine”. And at that moment, a tear rolled down my face, not because of the diagnosis, but because I had finally found a doctor that knew what he was doing and knew that my pain was real, and did not underestimate that. It was not normal to have intolerable pain or heavy bleeding. Fortunately, the two years I had spent in hospitals, without anything being done, had not affected any of my organs and my daily life significantly. After a complex surgery came a hard, long and painful recovery: six months of medical care, medical alert and restrictions, followed strictly by someone who wanted to fight with all her strengths.

Since then, and now at the age of 35, I’ve undergone two surgeries due to this disease that comes along often unnoticed, that slowly and insistently takes hold of us, sticking like glue. I have also made three fertility treatments, unfortunately without any success. In each and every one of them, it has been almost impossible to have access to my left ovary, as it is literally stuck to the uterus. Once again, endometriosis is to blame for that. I have taken more painkillers and birth control pills than I could ever imagine. Lots of tears and sleepless nights. But I know the disease now. I know what to do and how to do it and am being followed by a wonderful doctor that is a specialist in endometriosis. And even when people tell me, in every fertility treatment, that my body should respond much better, that I should produce more, that I surely have to feel “miserable” (yes, I have actually heard that from a doctor), I strongly believe that, all things considered, my body has been in fact behaving extremely well. I’m unbroken, full of faith and dreams, just like when I was 28 and made the decision of extending the family.

Today, I cannot say I have learned how to survive with endometriosis. This just isn’t enough for me. I will not subdue to this, I will do everything to set myself free from it. I live alert, but I have learned how to live. I am winning every battle against this disease, which may prevent me from being a biological mother, which may take me to a familiar hospital room, which may bring my old fears back, but will never steal my smile, nor my will to be happy.

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