

MUSEU DA PESSOA

História

“I won't be a paperweight”

História de: [Cynthia](#)

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Sinopse

Cynthia Macedo's story. Childhood spent in Belo Horizonte at a neighborhood called Prado. A new life with her mother in Balneário Camboriú, after the divorce. Career in Law and the diagnosis of Multiple Sclerosis. Impact of the diagnosis, the psychotic picture, depression and the reorganization of life. The creation of the blog “Multiple Sclerosis for lay people”, the conquest of the Tecfidera medication in Brazil. The cyberactivism.

Tags

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História completa

Cynthia de Sá Vasconcelos Mortimer Macedo was born on November 12, 1987, in the city of Recife, Pernambuco. Daughter of Paulo Mortimer Macedo and Gloria de Sá Vasconcelos and starting from them that Cynthia tells her life story. Her father started very young at Citybank, first as an office boy and then growing up to the position of vice president. This position provided a good economic condition for the family, but also brought the challenge of having to relocate from city to city. Due to her father's time dedication to the bank, Cynthia describes the home as a predominantly female occupation environment. The youngest of three sisters, she was eventually considered by Christina, the oldest, and Marina the middle, as the "doll of the house". It felt like having three mothers and being very cared for. The roaming of her father's work made him tired and, in addition, an entrepreneurial spirit eventually unfolded in the abandonment of his banking life and his investment in the automotive aftermarket. The family moved to Belo Horizonte, where Cynthia remembers the jokes in the Prado neighborhood house, between store tires and on the street with other children. Everything revolved around the workshop, the automotive shop. The house was next to the workshop. This was a time filled with fond memories, from a child's perspective, the house was where she played with her dog and the store was her favorite place for fun, since he liked to play with the tires in the workshop stockpile. Cynthia places this period in time between 1993 and 1997. Although Belo Horizonte is a metropolitan city, she played outside with friends, went to friends' house with some frequency and nevertheless mentioned the jokes at the school recess, which was very close to her house. Cynthia narrates herself as a bookish girl, learned to read early in school games with her sisters. And there, she practiced the writing of her name, in an American style, whimsically chosen by the sisters. Life in Belo Horizonte didn't come down to happy times. Cynthia reports that it was at this time that her parents divorced. The divorce itself was not traumatic, ponders Cynthia, the most traumatic being the fights. After they had separated they continued living in the same house, they were partners in the venture and this sharing generated fights. She takes stock and states that from age four to nine she lived in a troubled space. Under these circumstances Cynthia narrates that she had to take over as a “mini adult”. Life was no longer only filled with fun and it made room for crying, anger and hurt. In her analysis, this troubled period only passed when, after the divorce, she and her mother moved to Santa Catarina. In Santa Catarina, the family already had a house in Balneario Camboriu, which in the asset sharing was Gloria's and her daughters'. The sisters did not come immediately, Marina, the middle sister, stayed in São Paulo because she was taking a course and her boyfriend was from there. Christina, the oldest, had gone to live in the United States, as was her dream. Cynthia reports that this beginning in Balneario Camboriu living alone with her mother was very difficult, since she did not have the company of her sisters and now living in a new place with no sentimental references, besides the financial difficulties in the beginning of her mother's new life. Cynthia says that later, in mid-1998, Marina joined them. She adds that her mother started a job as a cleaning lady in a beauty salon, had a degree in Physical Education, but had given up her career to pursue a life with her father and at that point it was very difficult to start over. She became a beautician, worked in a beauty salon and has been in this field for 18 years. When Cynthia speaks of her sisters, she

repeatedly reaffirms the care and investment that her sisters directed in her educational background. Marina left school to work and help with expenses, took college entrance exams several times, but never found herself completely. Today she has a degree in Logistics, but does not work in the area. Christina married in the United States, made a living there and never failed to help her family. Once they arrived in Balneário Camboriú, was difficult to adjust to a new school, but over time the adjustment came, the financial situation was no longer the same, but she could count on the support of Marina and Christina who helped as much as they could. Generally speaking, Cynthia classifies adolescence in Balneário Camboriú as quiet. She remembers that at the age of fifteen she began her first serious relationship that lasted about two years, and others came until a decided break from dating, as she finds herself nowadays. She points out that she practiced volleyball inspired by her mother and life went on with her visits to her friends' houses, time at the beach and her studies. So at fourteen he decided to work in the summer seasons in local commerce. Cynthia describes her entry into the university as "curious." This is because it reminds her that in her teenage plans the goal was to study astronomy in the United States. And since her sister Christina and her father lived there, she thought the plan would be executable. Such a goal made devote greater concentration in the exact sciences subjects. Cynthia speaks without hesitation that the dream was to reach NASA. She even enrolled in an American school, but her student visa was denied. Frustrated, still in São Paulo to get a visa, she asks her mother to register her for a selection process, perhaps Journalism. But her mother decided that this choice didn't promise good income and enrolled her in law school. And so it happened. Cynthia studied law at Univali, Itajaí-SC, and fell in love with the field. Today considers that there was no better choice to be made. It was in January 2014, shortly after graduation and in the beginning of her career in a law firm, that she started to experience the first symptoms of Multiple Sclerosis. Committed to making the profession a selfless path that would be reflected in helping and transforming people's lives, Cynthia understood that she was not just dealing with paperwork. Behind the paperwork and court lawsuits there were people and life issues. She points out that this was one of the hardest periods in her life. She has always enjoyed reading and studying, and at that moment she mixed up the boundaries between work and leisure. But the office's results-oriented routine has made stress a constant companion in life, says Cynthia. Within this context, the first symptoms of Multiple Sclerosis began to appear. In December 2013, during her work recess, at the beach she felt a strong dizziness and suggested that soon it would pass. It was the first symptom of paraplegia that paralyzed her right side. While seeking medical attention, an otolaryngologist requested a resonance scan and found out that she had multiple sclerosis. At the peak of her career at age 26, and with many dreams to conquer, Cynthia states that the sensation was as if her world had fallen apart and the image that came was as a paperweight. Hospitalized for an emergency treatment due to right-sided paraplegia and a double vision picture, she received visits from her father and sister who came from the United States. It was a family reunion moment, when she described the impact of hearing about her future from some people who visited her. That is, they told her about her being in a wheelchair and about certain death. This picture terrified her. Doctors warned her not to look for information on the Internet, but her sister Marina had already done so and panicked by the life estimates she found there. Panic-ridden information said that a person with Multiple Sclerosis would only live five years or become a paperweight. However, her sister Christina heard good news in the United States and brought some encouragement. It was all very new and she still couldn't handle it. After leaving the hospital, she had a psychotic condition that led to a panic disorder. She thought she was being followed and was unaware of the new identity that brought the diagnosis. Cynthia recalls that these symptoms were very close to schizophrenia. It was in the search of herself that she created the blog "Multiple Sclerosis for lay people". The days of mental turmoil became a blog titled: "Sclerotic and crazy, now what?". After the psychotic breakdown, she had a rebound effect falling into deep depression. After the breakdown, she decides to return to work at the law firm in February 2014. Although the company verbalized support for her new situation, she realized the implications of the illness in the workplace. Before leaving for recess, she coordinated a sector in the office, no longer coordinated the tasks around her and her bosses reduced the demand of work. It was the moment of awareness that adaptation wouldn't only be in the body, but in life and social demands and then she ended up giving up this job. She reports a feeling of ingratitude for having been so dedicated. Cynthia left in October 2014 under court action against the bosses. This was another reason for the stress that unfolded in another outbreak. The blog was born at this time, it was necessary to write to witness the social prejudices of those who live around a person with a chronic disease. She points out that this idea honored the longing of being a journalist and the pleasure of writing diaries at an early age. Cynthia briefly retraces the path of the psychotic outbreak just to point out that the idea of the blog emerged in the reality lapses that intervened during the outbreak. But as soon as the lapse passed, there was the idea of starting a blog. The idea reappeared again when she contacted a blogger who also had sclerosis, Bruna Rocha, the first to create a blog in Brazil to talk about the day to day life with Multiple Sclerosis. But not much time passed between the conception of the idea and its creation. In March 2014 Cynthia created the blog. At first she wrote only with the intention of venting, putting it out. However, she recalls that in her reflections she was talking to herself: "Okay, I was diagnosed, but I will help people, I will not keep it to myself, I will do something with it. It will change my life in some way, but for good." The disease gave her a new perspective. Then she began to gather information about Multiple Sclerosis, filter it and pass it on to his blog readers. That is why he named the blog "EM for lay people". Cynthia recalls that in 2014 she found little information about the disease. Really different reality in the United States. There Multiple Sclerosis has a higher recurrence rate than in Brazil. Due to her relationship with the United States through her sister and father, Cynthia decides to create the blog in two languages: Portuguese and English. There was a turning point and the blog writing that went from being a kind of private diary to a platform for information and public utility. It was not something programmed, but pointed to some discomfort when talking about herself and was writing from a legal point of view, and that was why she was constantly judged. So she decided to invest in informing rather than talking about herself. Cynthia safeguarded that despite this, the blog has not lost its personal feature, that is, of an ordinary life. So much so that it is possible to find her personal history to acquire the drug Tecfidera. About this episode of her life, she says that through her sister, she managed to make an appointment with a doctor in the United States. Here in Brazil, she was medicated with Copaxone, the first SUS1 protocol medication, but did not adapt to it. At another moment, with the help of an American doctor, she obtained Tecfidera, which served her best in his treatment. However, the drug was not yet in the SUS protocol and she brought by her sister, came about fifteen boxes from the United States, she says. Her blog witnessed the entire judicial process to get his insertion in the list of self-cost medicines of SUS. Cynthia applies her legal expertise and wins the battle. She recalls that Tecfidera already had the approval of Anvisa, but had not yet entered the list of SUS, depended on a deadline to provide free. The blog gained space on its own, Cynthia said. According to personal data, more than 4,000 people accessed the space within approximately two and a half years of operation, and without sponsorship from pharmaceutical companies. Something she considers a feat. In 2015 Cynthia's actions gained an even wider dimension when she was invited to participate in a national meeting promoted by the Health Bloggers. From this point on, Cynthia is fully aware of the impacts of her social and political mobilizations. It wasn't something scheduled at first, but it happened. She has revealed that she has no intention of setting up an association in the region where she lives, but is willing to help organizations and people who are ill who need legal advice as long as she can.