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História

“Bad things happen, life is like that, learn how to deal with it, and move on”

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Sinopse

A life of care within a family in the countryside of Santa Catarina. A much younger son, two older sisters, grandparents nearby, father and mother routing carefully. An engineering degree and the security of a promising future in a favorable past and present. At the peak of his achievements a diagnosis of Multiple Sclerosis. A break for mourning. A time of discovery, a time of reflection and reconfiguration. Entrepreneurial achievements, new possibilities for a life with MS. Living in the present, many inspirations, past experiences and learning, and some unpredictable possibilities for the future.

Tags

- [Multiple Sclerosis](#)
- [entrepreneurship](#)
- [quality of life](#)

História completa

Raphael Odebrecht de Souza is the youngest son of a family from Rio do Sul, Santa Catarina. He recounts a boy surrounded by care. His father, João Carlo, loved to teach him the things of his world, clean weapons, tinker with tools and was the one who provided moments of fun, such as rappelling, mini-buggy rides, visiting different places. His mother, Deise Odebrecht de Souza, along with the other women in the family, his grandmother, his two sisters, Greici and Franci, surrounded him with care and pampering. She was also the one who took care of the discipline in school assignments and at the table in family lunches. He remembers a quiet life in the old and spacious house with a large garden, a basement used for a few years as the mother's production. There were several seamstresses there, which made his world always surrounded by women. He says he is more aware of his mother's family history. The Odebrecht who climbed the Itajaí-Açu River in the late 19th century, along with Doctor Blumenau, in the large German immigration project in the region. The same story told in the school benches, but also lived in the memories of his ancestors. Part of the family went to the northeast and part of the family settled in the Rio do Sul river region, becoming owners of much of the region's land. Grandson of a well-respected grandfather in the region, he has memories of a well known family, a father who left for work every day at the town hall of a nearby town, Agronômica, and a working mother in textile production. His narrative is reminiscent of childhood when his family house had many vinyl records, and he lying on the floor and listening to music with a headset. Perhaps this affective memory, coupled with his parents' encouragement to do something in the arts, influenced him to create a band in his teens. Dramaphone was the name of the group that kept Raphael and his friends busy on the weekends. He narrates moments of reception, full house, meeting point with friends who he still likes to receive at his house. Later, as a student in Joinville, his house was divided between friends and a common place where everyone used to meet. Still about the family house, some traumatic memories happened there. About the 1983 flood, he revisits what he has heard from his parents. It was on a day that they went out hunting and it rained, the car couldn't get in the way and they walked for two days until they got to the house. Another event was a loot that the family suffered while the city was in a state of emergency and his grandfather was armed vigil to defend the family. Raphael grew up listening to these flood stories that sounded like no amusement, but people told it as if it was something bad that he was understanding while he was growing up. In 1996 the water did not reach his house, but he remembers riding a boat around town. He remembers his mother hiring trucks to remove the sewing machines from the attic and the whole family moving furniture from the house upstairs. During the flood, while watching the rising water had nothing to do but rest and recover the body fatigue from the moving. He remembers 2008, 2011 and describes a scenario as a “war zone”, when the water goes down and people's furniture, refrigerators, a pool that came to a stand on a tree in the home garden. His school life was marked by school transfers, until he found himself as a student at Senai. Used to a private school, he remembers that he received little notes from the girls and suddenly that reality no longer existed. In technical school he fitted in mechanics, he recalls that his father had a taste for firearms and taught him to take care of them, disassemble, clean and parallel to this task he also enjoyed playing Lego early. Raphael believes these pleasures eventually influenced him in his career choices. When he finished Senai, he took a course in Mechanical Automation and briefly worked in a boiler factory, before his sister convinced him that he was able to take an admission exam for college. After

taking a college preparation course, he chose Engineering and got in to the Federal University of Santa Catarina, UFSC in Joinville. But, due to the difficulties of lack of structure of the campus, which was not yet structured in its first year of implementation, decided to transfer to the Mechanical Engineering Course of the State University of Santa Catarina, UDESC. Raphael reports as "phenomenal" the first year of the course at Udesc. He attended nine subjects and did very well in eight of them. For the first time he felt his competence and security in the face of his effort and dedication. He was a fellow at the undergraduate laboratory and that's when the first symptoms of the disease showed up. It was 2013 when he decided to do an internship at Embraco. Even at the beginning of the course, he decided to take up the challenge, manage class schedules, and tiredness began to come with his leg numbness. He talked to some doctors and decided it was nothing. The challenge of the internship increased, the required skills had not yet been studied at the university and in the face of great stress he had diplopia. He thought he was going crazy, after all duplicating the image of the boss in front of him. He sought an ophthalmologist who referred him to a neurologist. Startled, he reports that he left the office crying with fear of dying. He got a fit with a neurologist in Joinville who suggested a resonance. He returned to his parents' house in Rio do Sul, talked to his brother-in-law, who was a doctor, who calmed him down to wait for the resonance results. But the family began to hypothesize what it could be, and research the symptoms on the internet. Cancer was a possibility, but his sister suggested that it could be Multiple Sclerosis and he accepted the hypothesis better, since his great fear was dying and she tried to explain that multiple sclerosis wouldn't lead to his death. It was in this mood of anxiety that Raphael did the resonance in Blumenau. And while he continued his life at Embraco and at the university in Joinville, his mother and brother-in-law tried to access the exam report. Back home, everyone in the family already knew what he had and it was the mother who broke the news: "Rapha, it's multiple sclerosis." He reports that it was an extremely difficult week. He saw his father cry, he cried a lot and sought information on the internet about the disease. There was a scheduled appointment in Blumenau and in that appointment he was very nervous. He remembers shaking a lot and the doctor talked to his family for hours. He explained the history of the disease, which meant this diagnosis years ago without medication. And all the existing paths today. He prescribed Avonex, but his aversion to needles made him retreat at first. Remember that given the amount of resonances suggested he realized that his life would be different from non-sick people. "Outside the scope." Raphael describes how he saw his life before the disease as a predictable road, surrounding houses and trees, and a secure future ahead. But the disease was as if a dark mist were taking this road and he can no longer see the right future. This fact changed his present and his perception of life itself. He asked the doctor for a week off, which was the time to reflect on his new life. Pulse therapy began in Joinville, his mother accompanied him, and he describes the despair of a patient who is not used to the role of patient. He is frightened by the size of the needle to access the vein, he questions the amount of interventions and says he cried when he found himself in that helpless position. After the first two days of pulse therapy, when he was still unable to move his feet and was wheelchair-bound, reactions were returning and he felt that all was not lost. Friends came to visit him and the week of hospitalization was busy. But he didn't know the sensations of the body with corticosteroids and the first week after hospitalization was very difficult. Hypersensitivity, altered mood, severe fatigue, pain, insomnia and mild depression. The family tried to help with a trip, but he was very confused. In addition to all this came the feeling of abandonment of his girlfriend, who was a nurse and broke up with him because of the Multiple Sclerosis. His university and intern life at Embraco came back different. His attention was focused entirely on research about multiple sclerosis and the biological insecurity in the face of fatigue and possible symptoms. He slowed down the pace with the number of subjects, was well received in the lab, and decided to start medication applications. But he reports that it was a difficult time of his life, when the side effects of the medication were worse than the symptoms of the disease itself. It was a time of low productivity and constraints in the classroom due to limitations for the full yield of the subjects. He failed in some subjects, but on the other hand advanced on his findings about Multiple Sclerosis. He discovered Dr. Georg Jelinek's research into eating habits. He translated texts and related articles, changed his lifestyle, gained quality, blogged to share his findings, and refuted the use of medication that was so bad for him. Today evaluates that his life change was violent. He cut the meat, started swimming a lot, three times a week and felt very hungry. All energies were to guarantee the quality of life. He went to the market every day to make sure he had fresh vegetables, made his own food, yoga, swam, ran, and work activities lost priority. He assesses that the biggest challenge that the disease brought was to seek the balance between care needed for quality of life and dedication to work tasks and demands. Multiple Sclerosis brought the reflective experience to Raphael who decided what to submit his body to, but then evaluated his decision and can decide again otherwise. He recounts his cares marking this reflective empowerment of his actions. Gradually the energy of life was returning beyond the disease. He participated, with a friend, in the first Startup Weekend in Joinville. Developed an app so people with hearing loss could use their smartphones. With this idea they were Startup winners. They formed a team of ten people and believe this was a milestone that completely changed their lives. He learned about entrepreneurship and things grew, participated in other contests and continued winning: Inovativa Brasil, which is the largest startup acceleration program and won the Facebook award of eighty thousand dollars in service. Raphael participated with the idea of the innovation company Listen 9th Sebrae State Business Plan Competition and was the winner with a trip to Silicon Valley. He participated in Empreenda Saúde, in one of the largest hospitals in Brazil, Albert Einstein, Syrian Lebanese, and won fourth place. Closed the company after a long analysis, created other businesses, undertook, experienced new outbreaks of Multiple Sclerosis. He tested his body, accepted new medications, looked for new ways, recreated and reinvented. He believes that since he is aware of his body's unpredictability with Multiple Sclerosis, he is better prepared to live in the present tense, identifying the opportunities presented to him and open to decision-making even without certainty of a future. He recognizes that his past made him a dreamer and secure with a future and that his mother said bad things wouldn't happen, that things would always work out. The diagnosis presented him with an awareness of reality "bad things happen, life is like that, learn how to deal with it, and move on".