MUSEU DA PESSOA

História

"Thank God, I cannot complain!"

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Sinopse

Childhood spent in the neighborhood Iririu, in Joinville. Memories of a modest, cristian and united family. Youth marked by the desire of working early. Entertainment at dance halls on the weekends and a huge passion that becomes a wife and two daughters. The beginning of multiple sclerosis' symptoms in the midst of building the start of a life: studies, work, constructing a house and young daughters. In search of a diagnosis for almost 10 years. Rebuilding a life with multiple sclerosis, adaptations, gratitude and acknowledgment of partnerships and family.

Tags

- Joinville
- Multiple Sclerose
- youth

História completa

Ademir Pedro de Souza was born on February 22nd in 1974. He's the first born child of a couple that like so many others dream of a christian, honest, modest and healthy family. They were always residents of Joinville, Santa Catarina, but he's the only one that currently lives in the city, the others are at a beach house. The couple had Ademir still pretty young and soon after his youngest sister. He gets emotional when remembering his mother's affection towards him, and her embrace, that are still warm in his memories. His dad he admires for being "a man that never complains about anything," with precepts of honesty and truth that marked his son's life. Tells the little that he knows about his hybrid ancestry, his german great-grandparents, mixed-race grandparents and brazilian stereotyped parents. He remembers that the family experienced a very serious health problem with his sister, when she was still a baby. He reckons the priest at home and of everyone waiting for the child's death, remembers his parents crying a lot and his mixed feelings. Yet when narrating this episode he reinforces the family ties and the true friendship between them until this day. It's a memory that comes up in the context of affections in the face of the near loss of his sister and the childish perception of the importance of family and reinforces that, in the present, although they live in another city, they are virtually connected everyday. Like other boys his age, he played with his neighbors outside, played ball at the neighborhood court, getting into mischief that his father only got to know years later. The work life came very early. Still very young and against his father's will that desired that he had finished his studies. But the desire of consumption, like his older friends, had put him in a metallurgical factory at 15. Then, he discovered his work as a salesperson, at an auto parts store, and was fulfilled selling car parts and chatting with clients. As a teenager he went out to dance and flirt, and his blue eyes were a hit, and in between these experimentations he met his wife - the woman he assign his great love. Before he became 20, he discovered a great love and remembers with tenderness the time that they went out for a bike ride with other couples to the rim of the river, in the Joinville rural área. It was with this woman that, pretty young, was father of two daughter and beside her built their heritage. His girlfriend's pregnancy accelerated the wedding and at first, he lived in the back of this father's house, afterwards he bought land in a neighborhood far from downtown and built slowly a house. About this past he remembers that he felt very confident about himself, liked riding a bike, was agile and longed for his own business. He lived in the making of his house, worked without limits and finished his home. It was at this time, right after the wedding, in the middle of constructing a life, that he starting having symptoms of multiple sclerosis, but didn't have a diagnosis for almost ten years. He used to fall and not understand why, had difficulties to ride a bike, suffered fatigues on summer nights at the house in construction "that was hot like an oven" he tells. He didn't understand why he felt warmer than the others, tingling throughout the body and a sequence of badly slept nights. He felt like he didn't have speed and balance at the autoparts store where he worked, and frequently he dropped parts when him himself didn't fall down. He felt embarrassed among his coworkers that sometimes said he was drunk. Even with many struggles, he finished building the house and to get away from social constraints, given the limitation that he felt, he built his own business. But things didn't go well and weakened, he didn't get to be the successful businessman that he dreamed of until he sold the store and become again an employee. He went to a lot of doctors, did numerable medical exams and received a few diagnosis that took him to ineffective therapies. Until the diagnosis that gave him relief came. He hears about diagnosis that worked like a watershed in people's life, but in his story the diagnosis worked as a "big relief", after all, he needed an explanation for all the limitations in such a young body. Two years later, Ademir's diagnosis retired and at the time of the interview he lived in the same house, built

with so much effort, with his wife and two daughters. One of his daughters was engaged and he was proud of the beginning of her adult life and with the purchase of an apartment close to the family address. The three women of his life worked during the whole entire day and he stayed at home taking care gently of each detail. Sometimes, he starred a domestic accident, but while he narrated he didn't see himself in need of a caregiver. Methodical and systematic, he takes care of the garden, the backyard, the house and mainly of the kitchen, where he pleasantly welcomed the team for the interviews. He tells about the care his wife has towards him, Rosane: "[...] Rosane discovered I had this. I noticed that she didn't want suffering. She gave me even more love, staring taking more care of me." Beyond the love of his wife and family, he talks about the more intense approximation with the church after his diagnosis. In his narrative, he says that the education he got was catholic, but he wasn't diligente before the disease: "after I discovered the sclerosis I got more attached to God, and it changed a lot of things, very differently, and this is what is giving me strength to face it and not get discouraged". All of his narratives about the most difficult moments with multiple sclerosis were followed by similar expressions of the one he pointed out in his father: "but it passed, now a days is not the same it were before, I cannot complain." He confessed his faith and gratitude to God for the house and comfort that he achieved, his family's health and his wife and daughter's reception. He makes the kitchen his place of pleasure and care for the family. It's the place where he pleases his daughters and wife when he prepares tapiocas for breakfast, sweet potatoes for his daughter, the recipes experimentations that he discovers at a tv channel or at the internet. Ademir makes up recipes with fruits from his backyard and from the cakes and dishes he makes, he prepares his own life alchemy.