

Dehumanization in the Treatment of Parkinson's

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It was in 2011, at the age of 74, while in the specialty of midwife, when you were diagnosed, Parkinson's, then a year since the first medical consultation you went to with mom for an intermittent tremor in your right hand. Parkinson's, it was a blow to everyone.

The first five years of coexistence with your illness were good because it did not seem to be present but the reality was that the disease was advancing.

After this time we saw his face. New symptoms were added to the tremor.

During the day you were fine but, in the middle of the afternoon, you were beginning to notice that you were short of air. We couldn't know what it was, even if I was like a nurse, I could understand it. I thought it might be anxiety and try to calm you down, but it wasn't just that. Soon you started losing weight and in just one month you lost twelve kilos.

After several emergency services consultations, where they couldn't improve your condition or understand what was happening, they decided to join you for an in-depth study. They did all kinds of tests to finally conclude what it was about the evolution of the disease itself. The OFF periods began, periods in which the medication did not take effect and the disease presented itself as it was, so the dose of levodopa was increased to supplement the lack of dopamine, causing the symptoms of the disease. From this moment on my involvement with you as a daughter and nurse was essential. In the reviews now there were three of us, Mom, you and me.

After this new increase there was a long period of balance with your disease until 2019, when new companions appeared. You didn't want to go for a walk on the street anymore, you were afraid to be home alone and you were very dependent of mum because it made you feel safe. We also began to notice a slight short-term memory impairment. It was 82 years. This was a further increase of levodopa in the following neurological review. Now five steps a day. June 2019.

Dad, I know that you trusted your doctors a lot and me, until now you had done well and without more, you left your hands and under my protection.

But within weeks of this change there were new symptoms. Insomnia, daytime sleepiness, nocturnal enuresis, anxiety, delusions and agitation. It was already a difficult situation for the three of us, so we went to the health center that sent us a home care team to assess both mom and caregiver and you as a dependent. Mama had claudicated as a caregiver and you needed a stone ware in psychogeriatrics to regulate medication. And that's how it all started, Dad.

August 2019. First entry. It was rum 45 days in a partner where the regulation of medication consisted of add plus dose of antipsychotic. There was no improvement there, more on the contrary, you lost a lot of weight, a lot or time to be with yours, independent. You

didn't want to be there, you needed us, I know. But since they couldn't detect the origin of your confusion crises, they believed, and so they told us, that you couldn't go home. How could you do it if they weren't able to solve the initial problem? How did they not know that by lowering the dose of levodopa, the main medication for your disease, the symptoms that motivated your institutionalization could have subsided? I was very hurt by the zero training to manage the crises of your disease in a place that was supposed to specialize in this type of pathology. I felt powerless not being able to help you. And that's how you were sent to a private residence while you were on a waiting list for a final. For me it was heartbreaking, for you, a struggle to improve. September 2019. Second entry. You walked, talked, ate and dressed alone and calmly, I left you eating in the living room on your first day. But it vanished in just a fortnight. Every day that passed there was a great deterioration. Days when you were totally sedated, days when you couldn't maintain your posture, days when you didn't know how to walk well. "Yoli, get me out of here" you asked me please and yes, I had to. Not only was it that they didn't have a nurse, it wasn't just that they injected you with an haloperidol in secret, while they were denying it, being aware of the great harm it is in people with your illness, not only that dad, it's that they treated you badly, it's that they were totally dehumanized. They didn't treat you like what you were, an older person, vulnerable, dependent, with a terrible disease that even takes away your ability to laugh, to talk, to walk, to move, that causes you depression, anxiety, that leaves you nailed without being able to move forward, that trembles your body, on the outside, but also inside, and while those who live it, are aware of everything. In just a fortnight, you lose a lot of yourself. So yes, I had to get you out of there and I had to know how to do it. Taking advantage of a visit with your neurologist and having spoken to the rest of the family, it was decided that we would also take you to the emergencies of the same hospital because we felt that we were losing you and we did. I was to pick you up to take you to the neurologist, you didn't stand but the day before you walked. I asked what had happened and they told me you got up like this. In a wheelchair you came out of there, thus producing your first major deterioration in the evolution of your disease.

Already in the hospital, after going through the emergencies, they decided to put you in. You arrived with lung infection, malnourished, dehydrated, weight loss of 20 kgrs and a major advance in your illness, you couldn't walk, you barely spoke and you weren't able to do anything for yourself. I'm so sorry Dad, I know you trusted them and they hurt you, their mission was to take care of you, and they did the opposite. But we were able to get you out of there and provide you with the care you deserved and needed. The income lasted almost a month. Once you have uprated your lung infection and dehydration you were referred to a center near home to continue recovery and regulate medication.

October 2019. Third income. When you came the doctor gathered us to let us know. Your Parkinson was very advanced, you might not walk again, talk and still, further deterioration. You didn't talk, Dad, you were barely moving, you were very slim and you couldn't do anything for yourself and all that caused by a health institution when it was already worked was to take care of old men that for different reasons, they can't be home. The impression was that your soul was trapped in your body. It was really hard to assimilate the progress your illness had made in just two months. The goal there was to try to regulate medication and regain, if possible, some of your lost abilities. There were 45 days to do so, after this deadline if there was no improvement you would return to another residence. The days went by while changes were made to your medication trying to find the option for your condition. The first what they did was to reduce the levodopa, which from 5 you went to 3 because the medication itself that should help you alleviate the symptomatology is the same one that causes delusions, hallucinations and agitation, but you had to go through three centers, including the hospital, so that someone knew that it had to be done. And so one day, after so many, walking in the garden you said to me: "There's a lot of birds here". I didn't give credit, I had a hard time understanding you, but I did, at last your soul was connecting to your body. That was the first of many changes. Gradually you recovered what had been taken from you, speech, walking, eating alone, slept well and there was neither delusions nor agitation. Finally, after 7 months you were able to go home.

February 2020. At home. You gradually left adapting to being home again, with us, everything was fine. It was a month and a half later that confinement began because of the pandemic we're still suffering from. At the beginning everything was fine but in April they started night without sleep again. We tried to solve it by contacting the last center you was stay but it was not easy. With your illness and not being able to get out again you had anxiety crisis and you could not be able to receive medical evaluation by any means, again led to a crisis of confusion. In one of those crisis mom called emergencies because we didn't know how to help you. An ambulance came at home and after

the scan they decided to take you to the hospital but due to the pandemic situation we could not accompany you. Dad, how many times did tell you? We couldn't be with you if you were re-entered and you couldn't be alone and I didn't want to leave you alone. But it wasn't you, it was your illness that caused those situations.

May 2020. Fourth entrance. We couldn't visit you and the information from the new center was scarce. On the eighth day of this there we are called informing us that you are not well, you have a fever, you are more asleep. They did give us permission to visit you because for them it was a worrying situation. I come, your daughter, your nurse. When I arrived you were like in a state of semi-unconsciousness and sedation, but by telling you, "Dad, I'm here", you opened your eyes. I consulted with the nurse your treat. You were giving a medication that poisoned you, probably the cause of being so sedated. It was disappointing. Why did they give you a new medication without first asking your caregivers if you can take it? These were questions that hit me over and over since it all started. That afternoon and I squeamed you with insistence until I got you woken up and gave you dinner. You'd lost a lot of weight in just eight days, Dad, and it hurt me so bad to see you like this. Since that moment I could be going more assiduously to stay with you. The fever subsided, they even talked about sitting you down but, just a few days later, without having been able to it, the fever returned. They tested you for covid and isolated you. It came back negative but the fever didn't subside. To this were added breathing problems. You were wrong, I was sad, they didn't take care of you, I don't know if it was because of age, because of the health crisis, or just worked there, but they didn't, it was another place where it seemed not to value the lives of the elderly. No treatment for Parkinson, there was a lot of lack of hygiene, they didn't feed you and minimized the treatment for your improvement. Three days after the onset of the fever, the doctor called us requesting permission to inject sedation with morphine since it did not improve, morphine! That is, you enter to treat a behavioral problem, you are drugged so much to control it that it causes you to have a broncho aspiration, cause of your infection and, subsequently, because they do not know how to treat the infection or worse, as they believe that your improvement is not productive, they decide that you must die. I spoke to my family and decided it would be done according to the value I made after visiting you. Me, the nurse. When I arrived you were having trouble breathing, eyes closed and very hot, I carried my thermometer to assess, and they were over 38°C but I spoke to you and opened your eyes. I saw you, like other times in your hospital admissions when you had lung infection, but nothing that couldn't be solved with the right treatment. I didn't understand why they wanted to let you die without a fight. I called the doctor to talk about it, just as you were needing something that would make you expel mucus, besides antibiotic treatment, as on other occasions, however, he insisted on sedation with morphine again so I understood that they no longer wanted to do anything else for you. Again Dad, again they want to hurt you, again that I have to fight to be treated like a person. Why? Why doesn't the healthcare system care for its patients? Why is nothing done for people at a certain age? Why don't they value you the same way? After talking to my family we decided to request a transfer to a hospital to treat respiratory infection. I transferred it to the doctor, advising against it, but he accepted, in his words, "we were making a mistake". To the horror of your illness we had to add the pandemic, the cause of so many grandparents leaving, especially if they are going to places like this, in which I as a nurse have to explain what medication is to be put to my father and I as a nurse, I have to fight to deal with your current situation and avoid an induced and premature death. And what happened to those grandparents, who in the initial time of the pandemic, had no visitors? How many grandparents have left without it being their time?

No, Dad, it wasn't your time.

May 2020. In the hospital. On the second day, you stopped having fever and improved breathing function. The feeling that he had let a lot of grandparents go back to weigh on my head. Fortunately they let us accompany you at all times and I know that helped you. Due to your improvement and at your age decided to transfer you to a partner sanitarior to validate.

May 2020. Fifth income. The one you were going to now was a new one for us. Our surprise was pleasant, it was a center prepared for persons like you. We were already close to June and despite the restrictions by the covid, we were allowed to visit you daily, although always the same person. In this way I dedicated myself together with the medical team, for two and a half months, to try to recover your basic functions, those with which you entered the center that you went to looking for help stabilizing at the behavioral level and that you went out without any of them. After more than a month of flaking, several weeks without eating and without treatment, we gradually started with each of them, the most important, eating to start your medication, something that could be achieved within a few days.

I cried so much in those days seeing your condition, your extreme thinness, your shrunken legs, your broken soul. How many times you greeted me with eternal hugs! "My daughter, how good you are" you said to me, but Dad, you were my father as I wasn't going to be with you, as I wasn't going to try to ease a little the hardness of the illness that accompanied you, as I might not. It was curious to observe how without your treatment you had less symptomatology, fewer tremors, less anxiety, you looked like in peace. Gradually you started eating, talking, sitting down, although you couldn't walk, despite trying: "Yoli, get me up to walk" and try but you couldn't get upright, you had so much stiffness in your legs that you couldn't put them straight to support the weight of your body. It was hard to see you like this, but you've never been made wanting to live and out do yourself. Exhausted the time spent there and in the face of the impossibility, even, to move home due to your complications it was decided a new transfer to the center that you went in October 2019. And we were happy. You would can recover as you did the year before, but there was a limitation, we could only visit you half an hour a week and we knew that could affect your evolution.

August 2020. Sixth income. We were lucky and for a while we were able to visit you twice a week. You were making slight improvements, you looked happy. For the first month it was, and we were warned to be able to take you home shortly. You wouldn't walk again, it was, but at least you could be at home with yours. How much damage they had done to you in that place, that you couldn't walk again. We were like this during the month of August making two visits a week and calling the doctor regularly. Started in September we were called by the social worker to tell us that out of empathy with other families, it could not be two visits a week. We had to accept that. So, we started visiting you only once a week at a time when we were talking to your doctor to find out your condition. I called her at Monday to find out about you, but she was another, your doctor had gone on vacation. He explained that you made partial meals and that you had snot in your chest, so he started antibiotics, although there was no fever and he also removed the medication you were carrying chronic twice a day so that the snot would not be accumulate, which I do not yet understand. I went to see you on Wednesday, and I don't know why you were in bed. You were in snot, but they were mobilizing with a cough, we talked as usual, even though I saw you very sad. You asked me for food and you squeezed my hand tightly, and ask me not to leave and I kept all I could Dad. I gave you a hug, a lot of kisses, and we said goodbye until next week. Two days later at two o'clock at noon I was called by the new doctor to inform me that you were breathing badly and there had been a desaturation, having gone back, but that you were still with oxygen in nasal goggles. This had already occurred since you over the May lung infection. I asked him then if I could come and see you and he allowed me even if I only made two days from last visit, but from four o'clock, so worried I stayed home making time until the hour. Going crazy, they called me back. "I either feel sadly your father has passed away". The pain I felt at the time mi soul was split in two. I screamed and screamed in pain, without being able to avoid feeling empty and broken. I couldn't understand it, and Dad, still I can't. I imagine you were very lonely, tired of fighting and wanted to leave without disturbing. But it hurts, it hurts not only your absence, your departure, alone, while I was waiting at home so I could go there to be with you. It hurts me, that things didn't get right, it hurts me that they didn't see the gravity of your situation, it hurts me that they stop giving you your inhalers, your mucolytic. It hurts me that during that crisis not you were given the right treatment, and it hurts me to belong to a world responsible for your deterioration and your early departure. Because yes, you were older, but not your moment. Everything rushed because I didn't provide you with the necessary care for a long year in which I tried to help you for my profession. And I fought and I fought with a lot of colleagues who didn't take care of you the way it should be done from the profession. I'll keep fighting because I don't settle for it. Curious, curious that the same day you left us, 20 positive cases of covid appeared on your own page, right? And how bad things have been done to you, Dad, from start to finish. And what a year they've put you through where you've been slowly going through bad care. And how sad they belong to a world that is not prepared for diseases like yours and that the best solution is to let you go without doing anything to make up for yourself, because you were already older and you had no good to contribute to society. That life has been very unjust with you this last year that I have not even been able to shake your hand on your last trip after being all year round I fight so that you will not be taken away by dignity. How could you live for so many months with an arrhythmia without treating, an anemia without transfusion, a bedridden without anticoagulation, how? I'm trying to get back on my back and Mom's still sleeping on her side of the bed.

To your memory. My father, my hero. I love you, Dad.

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