

Parents Who Walk Away

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Denton Johnson's mother is often brusque and insulting. She has never been on time for appointments. She calls me "Lantos" rather than "Dr. Lantos," as if I'm some not very popular kid she knows on the schoolyard. "Hey Lantos," she'll say, "I need a refill on his Albuterol."

Her son, Denton, has cerebral palsy, mental retardation, and failure to thrive. For years, I've been trying to convince her that he is not eating enough and that he needs a gastrostomy tube. For years, she has responded by describing to me, in detail and in an increasingly weary tone of voice, just how much she feeds him and how much he eats at home, "Lantos, Lantos," she'll say, "He loves to eat. Last night he had meatloaf, and mashed potatoes, and greens." He is fourteen years old and weighs forty pounds.

The school nurse keeps sending me notes suggesting that I should report the family to the Child Protection Service for medical neglect. I could. They often miss appointments. Mom sometimes has a whiff of alcohol on her breath. Denton is malnourished. But I doubt if much would happen. She could beat that system cold. She'd show up for her court date well-dressed. She'd describe how much she feeds him. She'd promise to do better. She can be very believable. I know. For years, I've made "contracts" with her: if he doesn't gain a pound in the next month, we'll send him to the surgeon for a g-tube. "Ok, Lantos, Ok," she'll say.

Sometimes, she would manage to get him to gain weight, and then she'd return to clinic with a smug grin, aware of her success even before we weigh him. Other times, she would miss the next appointment and not show up for months. Then, when she'd reappear, Denton would have lost weight again, and she would have an elaborate and heart-wrenching story. She was in the hospital getting a hysterectomy. Her mother died. They were kicked out of their house.

I like her. She loves Denton. And I admire her. She is very good at what she does. She cares for him and advocates for him, according to her values. He looks happy. He is just really small.

Last year, after years of this, I told her that if she didn't take him for a gastrostomy, I could no longer be her

physician. "I cannot continue to care for a child who is severely malnourished," I say. If she doesn't get the g-tube and ever comes back to me, I tell her, I'll report her to child protection. To my surprise, she agrees to get him a g-tube.

What should have been a simple operation turns into a disaster. Post-operatively, he becomes obstructed. He needs a second operation. After that, I am not on service, and he is on the surgery service, but the interns keep me posted on how he is doing. Post-op, he is not doing well. He had an obstruction post-op. He needs a second operation. After that, he has a wound dehiscence. When I go to visit him, Mom is anxious and angry. "Lantos," she growls, "I told you we should never have had the surgery. He's losing weight. He looks awful. I don't want you comin' round here any more. I'm gonna find another doctor!" I try to explain that he's going to be ok, that I feel bad, that this is partly because he was so malnourished. That was a mistake. It was like I was blaming her. "Just go away," she says.

I wander out down the hall feeling like someone had kicked me in the gut. I'd never been fired before. I mean, I've had plenty of patients stop coming to see me. Many, I know, had found another doctor. But I've never had someone tell me to my face that they were so angry that they didn't want me to care for their child anymore.

I tried to decide whether I'd done a good job or a bad job for Denton. Oddly, she liked me better when I was doing things that most doctors would have thought medically inappropriate. I allowed her to allow him to become malnourished. I didn't report her to child protection. I preserved a tenuously trusting relationship with a woman who didn't much trust doctors or any other authority figure. It was only when I forced her to do what was clearly best for Denton that she rejected me.

Patients' anger or gratitude seems to have nothing whatsoever to do with whether I've done a good job. In some cases, I've made a difficult and particularly tricky diagnosis, or patched together a medication regimen that helped relieve persistent symptoms, or had a difficult conversation that led people to understand something about their child that they hadn't wanted to understand or accept. In such cases, parents seldom recognize that I've done a good job. A chart reviewer wouldn't either. I wouldn't get paid extra for such performance. There is no way to judge the degree of difficulty of the things I do. People measure things that are measurable. As the hospital administrators say, "If you can't count it, it doesn't count."

Making the correct diagnosis in this case was easy. The right treatment was obvious. The difficult part was making it happen. For that, we had to be willing to really wrestle

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with one another. I had to get so frustrated with her that I threatened her with legal action or abandonment. Then she got angry back, and hit me with all she had. We were both bruised. We had different sorts of power over one another.

Months later, to my surprise, I showed up in clinic and Denton was on my schedule. I was happy. I realized how much I liked his Mom. I liked the way she struggled with me, the way we could argue with each other, the way we had somehow gotten beyond “the doctor-patient relationship.” We had actually become part of each other’s lives.

Denton looked good. He had gained some weight.

I congratulated her on bulking him up, and told her that he’s looking quite buff! She said, “You know, I’m not even using the g-tube. When can we get it taken out?” I asked her why she thought he’d suddenly started gaining weight. “I’m just cooking more,” she says, “He’s eating better.” I look hard into her eyes for the little twinkle of deception. She stares back, defiant, inscrutable.

Maybe the best parents are the ones who struggle on behalf of their children, who recognize the risks and the imperfections in what we do, and who are not afraid to walk out on us. Or to come back.