

TRANSCRIPTION

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[0:00:10] My name is Eileen Chang, and I'm actually a patient safety coordinator in health care in the health care system. This is a story about my son Daniel and his journey through the health care system. He wanted to ensure that he was able to enjoy life as much as he could. He was always a team player. So for example, when he played soccer, he won the best sportsmanship award probably four or five times. By the third time, I went to the referee and I said, "Excuse me, but I think you need to give it to someone else. Are you sure it's him?" And they said yes. And the reason being is if someone fell in the field or someone looked upset because a goal was scored against the team, he would go up and console that person. So that's the kind of person he was.

[0:00:58] In high school, Daniel went on a camping trip as part of a school outing, and it was in the fall, in October. And at Christmas he would say, "Mommy, I don't feel well." And he kept on talking about his GI tract. Something wasn't right.

[0:01:14] We went to see the pediatrician and we would talk about the symptoms. "It's your hormones. You know, you're going into the teen years. That's why you're feeling that way."

[0:01:30] Many weeks after him experiencing this nausea, I receive a letter from the city where I live in Toronto saying, "Where did you get the drinking water?" So Algonquin Park is in northern Ontario. And when they went on the camping trip, they had to treat the water. So there's the treated water and the untreated water. So my son says, "You know, Mom, I always drank the treated water, but I did fall in the water at one point with a canoe, so I probably swallowed some water." So we explain that to the city. The physician, of course, prescribed the appropriate antibiotics. And it killed what was called giardia lombardia [ph]. And it's a water parasite.

[0:02:09] So I'm beginning with that story because that, I later learned, probably compromised his system. He was about to go to university away from home. He said, "Mom, I can't make it to even class without sleeping in my friend's dorm room." I go, "Pardon?" So then he started talking about symptoms like having a sore throat, swollen glands, and feeling really feverish. So because my sister lived not too far from the campus, I said, "You know what? Why don't you just call your aunt, buy a thermometer from the local drugstore, and have her look at the readings with you." He knew that he had to rest and he was able to get through the year. However, he always felt sick.

[0:02:51] He had then a plan and he had a girlfriend at the time who said she wanted to go to volunteer at an orphanage. And they were going to Peru. So you can imagine me as a mother, you're going to Peru? And that is really far. Going to Peru, though, meant he had to have live vaccines.

[0:03:12] Well, after he had the vaccines, his whole body literally crashed. It's like someone came along and just zapped his energy out. Of course, the nurse said, "Oh, that's just the side effects." And of course, you can imagine, the parent now, I have regrets. I should have brought him to the hospital right away.

[0:03:29] So we went through advice [?]. We thought he'd sleep it off. He never went to Peru, thank goodness. But his condition worsened. Again, the sore throat, the headaches, the pain he started having. And she looked at him. And again, same kind of thing is, "Oh, you know, you probably just, you know, are homesick." And I said, "No, he wasn't homesick at all."

[0:03:54] We went through all kinds of tests. One test actually tested his immunoglobulin result. And the irony is, it came back at such a bad level that she finally was convinced that this case, his case, Daniel's case, had to be referred to the experts. So I went with him. And I remember this was a pivotal point, I think, part of the journey. As I sat in the waiting room, and while I'm waiting, I'm looking at the magazine rack, because I can't sit still. And I said, "I've got to read something." And I said, "I'm going to read this journal," because something told me to pick it up. Well, it was really interesting. It was like someone was answering me because in this journal, it talked about every single symptom that my son talked about. It was as if my son wrote the article.

[0:04:40] So when I read the article, I thought, "Oh, my goodness, I have to get into this clinic where this physician works." And it was over a year wait time list. And I said, "Oh, my goodness." So Daniel, once he was able to be accepted as a patient into the environmental clinic, he was diagnosed as having myalgic encephalomyelitis. So finally, we had a name, we had a diagnosis, and it's something that we can relay to other practitioners.

[0:05:15] Common term is called chronic fatigue syndrome. It does not do it justice because people think that you're tired all the time. The actual term is myalgic encephalomyelitis. "Myalgia" is pain and "encephalomyelitis," "itis" is inflammation and "cephalo" is talking about the brain. Daniel was diagnosed at the time with myalgic encephalitis when the medical community did not recognize what that disease was.

[0:05:41] One can imagine as my son experienced, here's a 19-year-old talking about he's tired all the time, "You're just depressed." So he was stereotyped from day one. And he started then saying, "That's it. What am I going to do, you know, to encourage or bring forth education to these health practitioners?" So he made four YouTube videos. He

wanted to educate the world. He also was active in a Myalgic Encephalomyelitis Association or something [inaudible] of Ontario.

[0:06:18] The recovery to the disease is based on pacing. So one, for example, if I can describe it on a point scale, if one has ten points of energy for the week, one cannot go over this ten points. If one goes over this ten points, one is bed-ridden and you're taking steps back in the recovery. So my son learned to pace very well. In fact, he – and I was upset because I'm a mother – he said, "Mom, I have to go part time my studies." And I wasn't upset because he made the decision. I was upset because I didn't want to believe that his health was declining.

[0:06:54] After a year, so we're looking at 2011, around there, he was doing well in university. And then one day he said to me, "Mommy, my worst fear is coming true." And no one wants to hear that. And I said, "What do you mean? He said, I'm getting the pain." Because his pain had somewhat subsided. It was just more the fatigue and nausea that he was encountering. The pain was coming back fast and furious, so much so that he couldn't get out of bed in the morning. My son would feel really hot and really cold, but there's no temperature. His skin would break out. I mean, he never had acne, but he would skin would break out, so we'd get sent to the dermatologist. He would become sensitive to sounds. I love music. He says, "Mom, can you not play music?" My son used to play the piano. Nothing. It would be like a tomb in my house.

[0:07:53] And at that point, this is where things start taking a turn with his mental health. I was exhausted and we decided to have Daniel stay, you know, at another place, and his aunt and her husband looked after him. But unfortunately, my son saw an opportunity and he decided how to end the pain.

[0:08:12] So one evening, the day after I left Daniel in the other city, I was having my dinner and my mobile rings and it was Daniel. We had a plan that he was going to visit other practitioners in the States with his aunt. Daniel said to me, "I'm calling to say goodbye." I said, "Okay, he's saying goodbye to me now because it sounds like they're going off early." But he kept on saying, "I'm calling to say goodbye." And then I realized what was going on.

[0:08:51] And as I was talking to him, my front door opens and I wasn't expecting that door to open. But my boyfriend walked in and I wasn't expecting that evening. And as I'm talking to Daniel, he is not conversing anymore. And the extraneous noise in the background, I started realizing what was happening. He was outside. And I think I said to him, "You're not inside the condo, are you?" Daniel did not respond. And then I started yelling at my boyfriend to get on the other phone to get a hold of my sister and her husband.

[0:09:29] It seemed like a lifetime, and I can't remember how many seconds or minutes. And then the phone went dead. And I knew at that point his pain ended.

[0:09:37] This is why I would never wish this on anyone else, to make sure that as the journey through the health care system is there for each one of us, that we can at least reduce that suffering and provide the quality experience that any patient should go through. And myalgic encephalitis is another whole story. But I'm here today to talk about how we can listen to the patient and really understand that here, we have a patient who wanted to do the self-care, but no one was listening.

[0:10:12] My son was articulate. There are many, many individuals out there whose maybe first language is not English. There's the pediatric population. There are those who are not as fortunate as I am to be in Canada, to have the health care we have and all the specialists. And then we have the geriatric population. The patients and families often know what's best for him or her. And so when we want to engage and help, it's not because we're saying, "Okay, there's the solution. Give us the treatment." We're trying to also assist with that help.

[0:10:49] But my son said to me, "Just keep on talking to me." And that's the message I give to the audiences no matter where I am, and especially through Patients for Patient Safety Canada, that you have to keep on talking about it. And it's not about the story. It's about what we learn from the story and how we will deal with life situations differently.

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