

My eight-year-old son has a rare condition

What I'm telling him (and myself)

• By AVI JORISCH

Our doctor called about a year ago with news that no parent ever wants to hear. “The good news is that your son doesn’t have cancer.” I looked at my eight-year-old in the car’s rear-view mirror, and I suddenly couldn’t breathe. “The bad news is that whatever he has is incredibly rare and I don’t know how to treat this. From this moment forward you need to be your son’s biggest advocate.” I felt like I was kicked hard in the head. I was so shocked I thought I would get into an accident.

The roller coaster started 24 hours earlier after my son took a hearing test. He had sudden(?) “profound” hearing loss in his right ear – in other words, was completely deaf in that ear. He also has minor facial weakness and is speaking to some degree out of one side of his mouth.

Our doctor had called me earlier in the day and instructed me to go immediately to Children’s Hospital in Washington. At my son’s intake examination, the physician assistant went completely white. “You know what I am worried about, right?” I nodded. “A tumor.” Over the next eight hours, we saw dozens of doctors and capped off the experience with a “scary and loud” MRI machine. As we waited for the results, I felt dread. It showed nothing unusual.

I spent the next few months working my network and navigating the system. We ultimately started seeing one of the world’s top ENTs. Utterly perplexed, he told us quietly, “I am not going to sugarcoat this. His hearing in that ear isn’t coming back.” Our job was to rule out as many potential horrible diseases as possible, and determine if his facial weakness is degenerative.

The ENT felt it would take about six to nine months to be seen by various specialists. Ophthalmology to rule out vision issues; rheumatology (I admit, I had to look this up) to rule out autoimmune diseases; and genetics to see what my son – and most likely his mother and I – carries in his DNA. I thought to myself, “Are you kidding me? I’ll see you again in a few weeks.” I begged, called repeatedly, pushed, pleaded, and used all of my chutzpah to get the appointments in record time. I wish I could say that was the hard part.

I read *The Unexpected Gift of Trauma*, by Dr. Edith Shiro, a leading expert on post-traumatic growth. She promotes a framework to transform the human mind (and soul) through radical acceptance, followed by adopting new narratives. She encourages readers to view life’s challenges as gifts that can shape and metamorphize us into more resilient, even thriving, human beings.

Shiro was pushing on an open door. I have been very transparent with my son about what we know and what we do not. I watched his eyes go wide when I told him life’s greatest challenges also unlock our greatest superpowers. And this journey would give him the strength to navigate whatever comes his way.

I shared with my son some of the challenges I experienced as a child his age. I would often joke that I learned how to write property in college and think deeply in graduate school. “Baba, are you saying that even you are still learning new superpowers?” I smiled, leaned in and shared one of life’s most important secrets: if we are lifelong learners, we continue to unlock new and amazing capabilities for as long as we walk the Earth. My son liked that a lot.

I have seen my son transformed, becoming quite articulate for his age. When we go into doctors’ offices, I encourage him to lead and speak his mind. I watch with tremendous joy as he answers questions and banters with the doctors. I find myself watching from the side and seeing his blue eyes twinkle as my eight-year-old learns how to own the room.

Some of the insights the doctors have shared haunt my sleep and cause me tremendous heartache. Whatever he has is “sashimi rare”; “There is a chance what your son has is ahead of science”; and “All you want to hear is that I’ve seen this a million times and know how to treat this. I won’t lie to you, Avi.” Hearing this, I remain composed on the outside, but often feel terror inside. What parent wouldn’t?!

We have determined that the hearing in his ear won’t come back until there is a major breakthrough in modern medicine – and we are beyond grateful that he hears perfectly out of his other ear. The doctors cannot say with accuracy what caused this condition. To remain calm and make “reality my friend,” I go through my daily meditation practice and try to integrate radical acceptance, coupled with new potential narratives. I look for the superpowers that my son (and I?) will get as a result of this journey. I know that there is more to be revealed and that this is also part of life. Deep inside we all know James Baldwin was right: “Not everything that is faced can be changed. But nothing can be changed until it is faced.”

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