New Normal

Category: Stories
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When I finally got to take my newborn son home, after an almost six-week stay in the NICU, the social worker said, "You will be his advocate. You will know him better than anyone. And you will find your new normal."

My son's diagnosis was that he would never walk or talk. After his brain MRI, I felt that the hospital staff looked at us differently. My son's life—and, by extension, *our* lives—would be different. The challenges my family would face were unfamiliar to them. At that point, those challenges were unfamiliar to us, too.

To say that my family had a tough time adjusting is an understatement. Hundreds of hours of physical therapy, visits with numerous doctors and a couple of surgeries occupied the next decade.

Looking back, the social worker was right. I am my son's advocate. My husband and I, and his siblings, know my son better than anyone. He has significant disabilities, but he's smart and happy and loves to be part of the world.

We *have* found our new normal. We've found inclusive ways to explore. We have an adaptive van and go on road trips. My son has gone ice skating, hiking, swimming, surfing and skiing, all with adaptive equipment and supports. We've gone about our lives and have done an amazing job of integrating my son as best we can.

Caring for my son isn’t the challenging part. Neither is advocating for him. The hardest part about parenting my son is the constant repetition of his diagnosis. And it guts me every time.

I’ll be going about my day, getting work done, doing laundry or picking up the kids. The phone rings, and it’s the nursing company that provides a nurse on my son’s bus. The coordinator calls every two months for an update on his health.

I always answer the phone when it relates to any of my children, but the questions about my son’s health pull me back to another world and another time. Back to the early days in the NICU, when a cohort of doctors doing rounds would walk into the room, their faces in their clipboards, their monotone voices asking difficult questions. Questions they didn’t have answers for.

The coordinator’s questions over the phone are different, but they’re the same every time, and every time they sting.

“Does he still have seizures? When was the last one?”

“Does he still require food through a feeding tube?”

“Is he still fully dependent for all of his needs?”

“Are these terms accurate in describing his disabilities?”

We’ve found our new normal, but often, as we go about our lives, I’m forced to repeat his past. Forced to list his deficits in a cold, methodical way to people who see those words simply as black and white, rather than as daggers to the heart—difficulties I cannot help my son overcome, and challenges he will live with forever.

The bimonthly calls with the nursing company are only the tip of the iceberg. Each time we visit a new doctor, I must go over my son’s lengthy medical history—first with a nurse, then with a doctor. Through a state program, we qualify to receive reimbursement for self-hire respite care. Once a year, to renew his services, I must call the coordinators and, for twenty minutes, listen to them repeat every diagnosis in his records. When my son is evaluated for special education, his medical records are included, and I am asked to confirm their accuracy.

The last time the nursing coordinator called, I couldn’t take it anymore.

“Why do I have to repeat my son’s diagnosis so often?” I asked.

“Protocols,” he said. “We are an accredited agency, and the accreditation company requires a verbal update every two months.”

I understood, but after learning how to advocate for my son, I’ve also learned how to carry over that advocacy into my own life. And I just couldn’t take it anymore.

I called the accreditation company. I spoke with a very sweet woman and said, “I know the updates are for my son’s best interests, and that the company wants to make sure that my son is safe, and that his notes are up to date; but my mental health matters, too. Can we change the policy from a verbal recitation to a *written* confirmation? It’s much easier for me to read the diagnoses than to listen to someone repeat them, or even worse, repeat them myself.”

To my surprise and relief, it worked. Two months later, I received an email from the nursing coordinator. I spent thirty seconds scanning the notes, tweaked one comment, sent the email back and went about my day. Not having to engage with someone—to put on a smile and sound appreciative while they read my son’s deficits aloud, but never his accomplishments—made the task much easier.

Many people may have to live with lifelong challenges, but finding ways to manage them in the least invasive way is vital for both patients and caregivers. I need to keep my own mental health intact, so that my son and I, and the rest of our family, won’t miss out on any of our great adventures.