When life gets hard looking after my terminally ill son, I push right back

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The nurses didn't believe me at first, that my son could predict his seizures. They were chewing me out in the middle of his hospital room because I had hit the call button when he appeared to be perfectly fine. That's when Michael, only 11 at the time, yelled, "No! I'm not okay! I'm going to be sick!"

That was when they also first realized he could speak. He had a seizure two seconds later.

This whirlwind of physicians, neurologists, tests and hospitalizations had become the norm for Michael and me since he turned seven. It all started in the early hours of a Saturday in 2007 when his late father and I raced into his room to find his bed shaking and his face contorted to a look I had never seen before. At the hospital, he was sent for all sorts of tests. Eventually, they sent us home saying he'd just had a bad dream or eaten too close to bedtime. Then, it happened again a week later.

More tests and sleepless nights. More blame heaped on me, his mother, as his seizures increased up to three times a month. Once, when Michael was eight, a doctor with an idea on the tip of his tongue gave me a piece of paper that simply read "Batten." But when I presented this to another doctor, the possibility was dismissed, the paper plucked from my hands and discarded.

The weeks of waiting for answers turned into years. It was only when Michael was 18 that we got an official diagnosis. And it was Batten disease, a terminal neurological illness so rare and obscure that doctors came to Michael's hospital room to see it for the first time in their careers.

But that slow-burn search for answers is only half of our family's story. I'm here to talk about what comes after the worst day of your life. When you realize that every second you have left with your only child will be as difficult as they are precious.

The first thing I will tell you, as is the duty of every mother, is how handsome my boy is. So much of his father lives on in him. He's always dressed smart as a tack. At 22 now, Michael has never been one for jeans and sneakers. He wears loose slacks and loafers, even if his loafers have Velcro instead of laces, according to the doctor's instructions. He's classy like that. It's a mark of self-respect, to dress nicely even though we haven't been outside in over a year, even when aggressive treatments have taken away his speech and mobility, and he spends most of his time in bed.

My boy also loves to learn. No matter how much he was bullied for his condition or the colour of his skin, he loved school for as long as he was able to attend. He loves faith, too. (So do I.) Whenever our local bishop comes to see him, they talk about prayer, communion, and fundraising for hours. That's who my boy is: calm, engaged, sophisticated at heart.

Life with Batten disease is round-the-clock. Caregivers and support workers come in and out of our home. Our regime is strict. The home is spotless. I track absolutely everything: activities, medications, a record of seizures so detailed our doctors keep my notes on file. When we find what works, we stick with it. No pill has been skipped. No appointment missed.

Still, one year a teacher did call Children’s Aid about Michael, seeming to think I made my son sleep in a cupboard. At school, Michael had eventually struck back against a bully, and between that and his seizures, someone thought the matter needed to be investigated.

Such blame and suspicion are protocol for single Black mothers, even those whose children don’t have rare diseases. I think part of my attention to detail comes from a need to constantly prove myself. When doctors spin me in circles instead of listening to my concerns, I leave them in tears with threats of going to the press and the College of Physicians and Surgeons. That Children’s Aid worker admitted I keep my house better than her own, and they never bothered us again. Just like our doctor told them: “No child gets better care than Michael.”

People ask me why I don’t put my son in a home, and I have to resist the urge to slap them. This assumption that children with disabilities are unwanted, when really, I feel chosen to be Michael’s mom. I believe God doesn’t give us more than we can handle, and we’ve been blessed with the kindness of our community and strangers alike. Even caregivers who are no longer on our care team often keep in touch (like I said, they all love my son). With everyone’s help, when things get challenging, I’m ready to challenge it right back.

I have to wonder how many kids like Michael are out there who don’t get the care they need, either for the colour of their skin or the obscurity of their illness. We need so many things: more research into a cure, genetic testing for Batten disease during pregnancy and, most importantly, the breaking down of racism, sexism and the stigmatization of disability.

And one more thing: Don’t ask me not to cry, and don’t expect me to wish my son were any different, as if that would make him easier to love. Michael was born for a reason, to be loved like any other child. He will see and hear that love every day, until the end of the end, and I will have been grateful for every second.

Jennifer Rochester lives in Toronto.