

FIRST PERSON

I don't want to live forever. I want to live a day longer than my dependent son

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CONTRIBUTED TO THE GLOBE AND MAIL

My eyes fly open, my body is tense. I've dreamt again of losing my son in a crowd. The panic and desperation in the dark feel completely real. I can't let go of the responsibility lodged in my body, even though my dependent son is 24 and recently moved out with lovely, caregiving peers and friends. Even though he's a 10-minute walk away and his living situation is ideal, my heart pounds in the night.

Ges, pronounced Jess, will always need support with self-care and life management. That care isn't hard for me; I can handle it. By now, it's hard-wired. It's time-consuming and draining, but doesn't involve feeding tubes, seizures, chair lifts, medication schedules or ostomy bags. It could be harder. But my doctor might say it's taken its toll.

My long-term stress still keeps my fight-or-flight response active, and caregiving's long-term effects seem to have caught up with me. My doctor

refers me to a rheumatologist, cardiologist, dermatologist, pulmonologist and gynecologist.

The laid-back joy of playing pétanque with the locals in Laos

Ges won't become independent. It weighs on me that, as capable and caring as his paid caregivers are, no one will love him as I do. My protective urge wakes me in the night. I don't want to live forever; I want to live one more day than him.

Many caregivers face similar dilemmas – balancing self-care with caring for others. My approach to mothering has left little space for myself. I'm not complaining; I have plenty of resources and support. My choices are mine. But it's still difficult. Society makes it that way. My son's impairments aren't what make him disabled or cause my stress. It's what comes at us.

When Ges lived with me full-time, I could only be as dependable as the people we hired to care for him. So whenever one of our part-time staff members cancelled, I would set aside my tasks to stay with Ges. But there was a time not long ago when his worker cancelled at the last minute, and I chose to take him to my specialist appointment. I couldn't rebook; I'd waited months.

The thin-lipped, furrow-browed, stony faces in the physician's waiting room did not appreciate my 6-foot-2 son waving back and forth in his chair, gripping his phone at chin level with both hands, his baritone guffawing at a YouTube cartoon. They tried to catch my eye to convey their disapproval, but I'd experienced this kind of judgment many times and I avoided eye contact. Their disdain paled, however, compared to the debate with the medical office assistant about whether to bring him into the large examining room.

I had a hard time connecting with our baby until one long lonely night in the NICU

“He can't be here with you,” she said at the doorway. Ges looked at me questioningly, his hearing is perfect.

“He has developmental disabilities. I need him here with me so I know he's safe.” Hands on her hips, she apprised me for a long moment, then slapped my

file onto the counter.

“I’ll need to ask the doctor,” she snapped, leaving the door open. The veiled possibility of his expulsion trailed her down the hall.

Whatever. I’ve stopped caring about reactions like hers and the people in the waiting room to try to make Ges’s presence okay for them. He’s perfect as he is. I shut the examining room door loudly. When she returned, I fixed my neutral, rehearsed expression on her. But inside, my neural system surged, trying to calm my nerves, unclench my jaw and relax my muscles. He’s allowed to stay, but she was clearly unhappy about bending the rules for us. Feelings of “you’re not welcome” here lingered.

Ges’s story isn’t as uncommon as you might think. Nearly eight million Canadians over the age of 15 have one or more disabilities. This could be an acquired impairment or a lifelong rare syndrome like my son’s. Maybe it’s the person checking your groceries whose body is always in pain; they’re working because they need the paycheque, not because it’s good for their health.

Long-distance calls with my parents can be about nothing, but they’re also about everything

Caregivers manage their own lives while being deeply involved in often complex care for someone else. Being with Ges has never drained me or sent me to the doctor. What exhausts me is the world around us. Parents like me tend not to share our stories. We have private chat rooms, trusted friends or family for that. We don’t voice our experiences because we don’t want to sound whiny. We especially don’t want charity or pity.

Ges needs people who notice him *and* value his uniqueness. Yes, his mind and body work differently because of his impairments. But his health condition doesn’t disable him unless he is excluded, misunderstood or devalued. Who says a person in a wheelchair is disabled? A world of stairs. My son’s disability is created in the waiting rooms of doctors’ offices, in the biases embedded in our institutions, and in how we treat him and each other.

When we notice *and* value one another, we all feel like we matter. It only take a moment of care.

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