

PARENTING

I'm coming to terms with being a mom with a chronic health condition

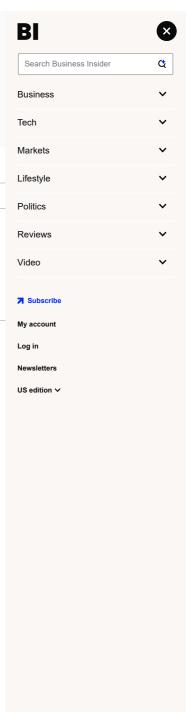
Essay by Jenna Glatzer



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- Scarring in my vocal cords has affected my ability to
- My daughter often has to speak for me for example, she's had to ask for quotes for repairs.
- On top of struggling with a chronic health condition, I feel guilty as a mom.

Parenting with a chronic health condition sometimes makes me feel inadequate. I remember when I was the parent I wanted to be: active, engaged, ready to take road trips to amusement parks and pick up my daughter's friends on a moment's notice.



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But during her teen years, a <u>vocal disorder</u> I'd had for years reached desperate levels. Suddenly I could no longer speak above a whisper, and my throat began closing unpredictably, leaving me <u>unable to swallow</u>, unable to sleep for more than a couple of hours, and couch-bound for days at a time.

We would just watch TV and hang out

I stopped making plans entirely. I never knew which days would be just moderately bad and which would be torture. I couldn't host any more sleepovers or take vacations with her. Many days I spent sitting still, just trying to breathe and eat and get my throat to open up. We watched more television than usual, and she did a lot of drawing and writing.

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What a waste of a summer, I thought. At least I'd already had 45 other summers. She'd had just 14, and this would've been a great one — if not for my "stupid throat thing," as we called it.

When we faced the world, she had to do all the talking for us. That meant everything from asking for quotes for home repairs to providing my order at Subway. I'm far less able to function in society when she isn't with me.

It makes me feel guilty

On top of the difficulty of my illness, now I had guilt. All I wanted was to be the old me, who my daughter could count on for anything. Now I was asking her to accept a broken mom and to fill in for my gaps.

While I still feel heavy about what we've both lost, I've also had to learn to give myself grace. I didn't ask for a chronic illness, and I really am doing the best I can. I've tried to see the positives in this for her — for example, I'm watching her interact more easily with adults now because she's gotten used to taking the lead in conversations. She approaches people she never would have before, and it's snowballing.

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"I'm going to try to talk to three new people today," she told me recently — a feat for someone who's always been on the shy side.

She's gaining empathy and life experience. When a theater troupe recently did a comedy skit with a character who can't talk, she asked me, "How was that for you?"

Hard. It was hard to watch an audience laughing at a character like me.

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But my daughter, who aims to be a graphic novelist, is forming stories in her mind that won't use illness or disability as a punchline. Her friends ask her how I'm doing. They won't make people like me into jokes either.

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We all need some grit in our lives; it helps us grow and appreciate the good times even more. And we do still have good times — they're just more spontaneous now. When my throat isn't seizing, we take advantage of our

I want to believe that one day we'll be able to look back on this time and think, "That was tough, but I'm so glad things got better." And if they don't, I want to believe she'll always know a mom whose spirit is stronger than her body.

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