



PERSPECTIVE

How IBD Has Shaped My Approach to Parenting

Written by Bridget Shirvell on August 18, 2021 — Fact checked by Jennifer Chesak

My toddler may not understand what an autoimmune disorder is yet, but she is still learning valuable lessons in empathy and compassion.



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“Wanna see, wanna see.” Toddler speak greets me as I step through my door. My daughter is already at my side, demanding to see the band-aid from my latest Entyvio infusion.

After touching the rough, pink self-adherent tape wrapped around my left arm, she immediately wants me to take it off and see underneath.

She peers closely at my arm, examining the skin for any trace of an injury

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This is our bi-monthly routine. Every 8 weeks, I receive Entyvio, a biologic therapy, through intravenous infusion. It keeps my **ulcerative colitis (UC)**, an **inflammatory bowel disease (IBD)** that causes long-lasting inflammation and ulcers in your digestive tract, under control.

My daughter has never seen the actual infusion, mainly because COVID-19 protocols mean I go alone for them. Still, even before the pandemic, I always scheduled them around my part-time childcare, having no idea how I would keep an active toddler from wreaking havoc at the infusion center for the roughly 30 minutes I have to keep one arm relatively horizontal and still.

But she knows her momma goes to the doctor and always wants to make sure there isn't a boo-boo when I get home. I try not to read too much into that obsession, although sometimes I wonder if years from now, along with masks, she'll dream of pink bandages.

At age 2, my daughter isn't capable of understanding colds, let alone an invisible autoimmune disorder. But while my UC is thankfully under control, it's likely only a matter of time until I have a flare-up again.

Even if I don't, eventually, she'll ask more questions about the visits. As she grows and starts to have a life more separate from mine, we'll have to have more talks about what **immunocompromised** means, the importance of things like flu shots and other doctor-recommended vaccines, and all the other ways my condition could affect her plan for any given day.

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I wasn't prepared for parenting through a flare

Diagnosed with UC when I was 19; by the time I had my daughter at 33, it was such a regular part of my existence that I, of course, spent time thinking about [how UC would affect my pregnancy](#).

If you're having a flare-up (I was not) when you get pregnant, you're less likely to reach remission during pregnancy, and my OB-GYN cautioned there was a slight chance it could mean a preterm delivery.

My primary doctor, who coincidentally also has UC, warned I might have trouble breastfeeding and might experience a flare-up post-delivery due to the changing hormones.

I prepared for the practical part of those side effects. I had contingency plans if the baby came early, a freezer full of frozen food, and friends and family eager to help in whatever way they could.

Yet somehow, I spent almost zero time thinking about how my UC would affect my life as a parent. It just didn't occur to me that all the slight adjustments I make when I'm not feeling 100 percent — sleeping more, changing my diet, staying home — would be more complicated, if not impossible, with a child.

Then I got sick. Really sick. The kind of UC flare I had never had, not even when I was first diagnosed, and it took months of tests and various medical visits to figure out what was going on.

Usually, I have a warning when a flare is coming, little ways my body starts to feel that I've learned to recognize and often allows me to prevent a full-on flare. But this went from 0 to 60 in the blink of an eye.

I was so exhausted that putting on socks made me want to go back to sleep. Coupled with wanting easy access to a bathroom at all times, just in case, I started not wanting to venture too far from home.

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IBD has made me a better parent

I learned a lot during the first year of my daughter's life, when my UC was out of control for 8 months.

For starters, there are a lot of ways to interact and play with your child while lying on the floor. But I'll always be jealous of the people without a chronic condition who get to spend time with my daughter, doing something as simple as tossing a ball back and forth in the yard, spending an afternoon at the playground, or taking a walk on the beach when I have to consider my pain level.

One of the most important lessons, however, was that, weirdly, UC makes me a better parent.

Of course, I want to gift my daughter with a magical, dreamy childhood. But even without UC, that wouldn't be practical.

More than anything, I want my daughter to grow into a happy, kind, self-sufficient person. To do that, I need to teach and show her how to be a grown-up, face scary things, have compassion, and advocate for herself and others.

She may not yet understand autoimmune disorders, but she understands what I mean when I say my tummy hurts or even if a friend of hers isn't

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Eventually, I'll ask her to join me for an Entyvio infusion, so she'll see how it works. Through the years, she'll experience watching me navigate the medical system and advocating for myself.

More than the practical aspects of UC, it forces me not only to take advantage of the good days, but really to also make them all good days, whether that means sitting on a couch and watching a movie or waking up to a beautiful morning where I can put off staring at a computer screen for a bit and we can take that walk on the beach.

Bridget Shirvell is a writer living in Mystic, Connecticut. Her work has appeared on Civil Eats, Martha Stewart, The New York Times and more.

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