

Having a Chronic Illness Helped Me Prepare for the Uncertainty of the Pandemic

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PERSPECTIVE

Managing ulcerative colitis means accepting the unpredictability of life.

Chortling filled the air as my 1-year-old ran towards the water, only to be scooped up by her uncle on the nearly empty beach in Pacifica, California.

It was the day after Christmas, and she'd been running around the beach for at least half an hour with my brother and sister. The four of us were the only ones from our family left in town after the holiday celebrations.

It was impossible not to smile watching the three of them, but I was also envious. In the midst of an ulcerative colitis (UC) flare-up, I had felt well enough when we first arrived at the beach but now felt too sick to do more than sit watching them.

I'm fine, I'm fine, I told my siblings. *I'll sit over here, no need to change our plans.*

I was diagnosed with UC — an inflammatory bowel disease (IBD) that causes long-lasting inflammation and ulcers in your digestive tract — when I was 19.

I've lived my entire adult life managing my illness and the uncertainty of not knowing how well I'll feel at any given moment.

It has long impacted the type of plans I make and whether I make them at all. Little did I know, while jealously watching my daughter and siblings that day, that all my practice managing expectations and taking things easy would come in helpful during the global pandemic that lay ahead.

“One of the things that I've noticed with clients during [the COVID-19 pandemic] is that some of them try to hunker down and wait out the pandemic, while others are more willing to find creative solutions to get their needs met,” says Ned Presnall, LCSW, a social work professor at Washington University in St. Louis and director of clinical services at [Plan Your Recovery](#).

“It may be that people with chronic illnesses have more experience engaging in creative problem-solving, so they may be better prepared to creatively compromise during the pandemic as well,” he adds.

Hoping for the best, planning for the worst

When the pandemic forced much of the northeastern United States to shut down in mid-March, I didn't find it particularly hard to stay in.

I've lived through flu seasons where needing to be on the steroid prednisone (which can inhibit your body's ability to fight infection) for a flare-up meant I washed my hands 20-plus times a day and only left the house when absolutely necessary.

If anything, the most frustrating part was the hoarding happening. I briefly worried I wouldn't be able to get the brand of diaper wipes that doesn't irritate my child's skin.

As the pandemic continued, it became clear things weren't going to be back to “normal” by late spring or early summer, as many of us had thought in March.

So, I started doing what I've done since the days even before my UC diagnosis, when I was visiting doctor after doctor trying to figure out why I had no appetite, had lost 20 pounds, and was so tired — hope for the best, plan for the worst.

Hope you can run around the beach with your daughter, be OK watching. Hope you can have dinner out with friends, be willing to ask if they'll come to you with take-out instead or be OK canceling.

Hope (and work pretty hard with your care team to ensure) you can go on the planned reporting trip to Ecuador, figure out a plan A, B, and C to make it work, but also be prepared to have to pull out at the last minute.

Managing a chronic illness means accepting the unpredictability of life.

Translated for pandemic terms, it means hope the store will have flour, but order it online just in case. Hope your dad can watch your daughter for a few hours so you can work, and ask your best friend for help when someone at your dad's office is diagnosed with COVID-19.

Hope you'll be able to eat out with friends, but be OK with leaving or asking to move tables if physical distancing isn't being enforced. Accept that life is going to be uncertain for probably another year, if not two, and create new routines around this new normal.

"People have to accept a degree of unpredictability that can feel frustrating," Presnall says.

"One way to deal with this is to have a routine that is followed during a flare-up," he adds. "Routines are ritualistic, and they can make us feel more in control during uncontrollable moments."

Over the past few months, I have managed to carve out a daily routine, and it has helped. Still, I'm dreading this upcoming winter in the Northeast.

During the summer, it felt like a brief respite. I could go outside and see friends from a distance while wearing a mask.

Soon, it will be too cold to do that enjoyably.

I imagine many people are feeling similarly, even those not managing a chronic illness.

Setting boundaries

Over the years, my disease has forced me to be painfully honest about what I need and make no apologies for it.

"Having a positive outlet, having self-compassion around your expectations, and self-advocacy is super important in being able to manage this time," says Akua Boateng, PhD, a Philadelphia-based licensed professional counselor. "We have high expectations to be resilient, but what's more important is to ask for what you need."

Asking people if they've gotten a flu shot and saying "no" to meeting them in winter months if they haven't, has now turned into leaving the grocery store if people aren't wearing masks and calling the manager if employees aren't.

ADVERTISING

Practicing self-compassion

Living through this pandemic is so hard, but we all have to be gentle with ourselves.

As a friend has told me over the years, stay focused on your own yoga mat. Don't compare the poses happening on your mat to someone else's. It's good life advice, too — especially now.

We're *not* all in this together, the pandemic won't hit all of us the same, and you can't compare experiences or expectations.

You can, however, be kind to others and yourself.

Bridget Shirvell is a writer living with her family in the Bronx. Her work has appeared on Civil Eats, Martha Stewart, The New York Times, and more.

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- Boateng A. (2020). *Personal interview*.
- Presnall N. (2020). *Personal interview*.