

Lessons from my first quarantine

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In 2003, my husband and I, along with our three young children, were trapped in our home for six months, as our finances fell to pieces and our 3-year-old daughter, Gracie, fought for her life. That winter, Fifth Disease, a classic childhood illness ran through my son's kindergarten. Fifth Disease is a type of parvovirus that's usually mild and causes a low-grade fever and rash. I was more worried about all the other "bugs" going around at the time: the high rate of influenza, RSV (Respiratory syncytial virus), rotavirus, and other respiratory diseases.

Then my daughter's preschool class came down with Fifth Disease. Gracie got sick, but her rash looked different than my son's. She stopped using the bathroom, lost interest in food and became lethargic. On a trip to the pool — her favorite place — she didn't want to swim and had to be carried to the car.

I knew something was seriously wrong. It turned out that Gracie had a very rare reaction: She went into cardiac shock and developed viral myocarditis, which prevents the heart muscle from pumping. That year, New Zealand saw three cases like Gracie's. One patient lived, one died, and one needed a heart transplant.

Gracie went from the ER to the ICU and then was sent home because she was at high risk of catching another virus and her immune system was incredibly fragile. At home, she was attached to monitors and oxygen therapy and I gave her 16 doses of medication a day. At times, she was unable to process the medications orally and I had to bring her back to the hospital for an IV. By the time that she was referred for a heart transplant, she had lost a third of her body weight and was deemed too fragile for the surgery.

While Gracie was ill, my son became sick with the flu. For two weeks I cared for both of my sick children, changing gloves and gowns between their rooms. Our family stayed home, and away from others, for three months, and then had very limited interactions for another three months. We had to keep Gracie safe.

My boys, who were in kindergarten and second grade, were home with me. We did so many crafts. We played games. We came up with goofy ways to brighten the days — we'd only communicate in opera singing for a day, or we'd all do a funny walk.

We depended on friends and family to bring by groceries and relied on my kids' teachers to check that they were making progress on their schoolwork.

Then, one day, Gracie's EKG improved. Slowly, she got better. By age 6, she was off medication. By 13, the thickening of her heart muscle, thought to be permanent, had miraculously disappeared. She's now a competitive soccer player and nursing school student. I share this story, because I know some of you wonder if the people working in public health understand how difficult all the changes brought on by the COVID-19 pandemic have been, or how much sacrifice it involves.

I do.

Not all stories are alike. I am no longer fighting to save my daughter's life, but I am fighting for our community. I face the same challenges and limitations many of you do. My oldest boy is quarantined north of us. This year, my second son will graduate from college with no fanfare and no family. He is living abroad and cannot get home. Gracie is living at home for now, her plans put on hold. We all feel rattled and weary.

But I also want to share some hope with you. Our family's life never returned to "normal" after Gracie's illness, but we did find a new balance. We also built stronger bonds. We loved more and were more compassionate and more grateful. We got through it together. And I have to tell you, after going down that dark road, I feel braver on this one.