

Crohn's: A Day in the Life

By Kristen Weiss Sanders, as told to Barbara Brody

I'm a biology professor, and on the first day of class I always tell students about my backpack because I don't want them to waste time wondering why I'm wearing it all the time. I say, "This is a medical device, and it contains an IV pump. I have a disorder called Crohn's disease. I had a large portion of my intestines removed, so in order to stay adequately hydrated I need IV fluids. I don't have cancer, I'm not contagious, and I'm not dying."

I'm 32 now, but I've been living with inflammatory bowel disease (IBD) since I was a junior in high school. My initial diagnosis was ulcerative colitis, but it was later changed to Crohn's. (Both are types of IBD, but

Crohn's causes inflammation throughout the intestinal wall, not just the inner lining.)

I've had many surgeries over the years, so my intestines are much shorter than they should be. For a while I had a J-pouch, which collects waste in an internal reservoir so you can still have bowel movements normally. But I eventually needed to get an ostomy. It's an opening in your abdominal wall that a small piece of intestine, called a stoma, passes through. I nicknamed my stoma Roo, as in kangaroo, because it empties into an external ostomy pouch.

My ostomy is so high-output and I lose so much fluid through it that I have a hard time staying hydrated. That's why I need to often run IV fluids. They're stored in my backpack and attached to a pump that connects to my body through a port. I once flew to Europe with 14 bags of IV fluid.

I usually have to empty my ostomy bag six to eight times per day, but since June I've had a severe motility problem and haven't been able to eat without vomiting. At the moment I'm on IV nutrition (total parenteral nutrition, or TPN), which gets infused along with saline through my port.

Redefining Remission

Despite how sick I've been lately; my Crohn's is technically in remission. The inflammatory markers in my blood are normal, and my last endoscopy didn't show excessive inflammation. But I've had so many surgeries over the years because some of the best medications, including the one that's currently keeping me in remission, weren't on the market when I was younger. Now I'm facing the fallout from all those procedures. Sure, it's great that I don't have active disease, but for me remission isn't all it's cracked up to be.

Every person with Crohn's is different. Not everyone who has it deals with the same problems. Most people don't realize the sheer amount of time and effort it takes to keep myself going. I once taught a class with one ear bud in because I was on hold with a pharmacy and about to run out of eight different medications. If I hadn't gotten my meds in time, I would have ended up in the hospital.

I get my daily oral medications packaged by the pharmacy into "morning" and "evening" packets, and I use an app to remind me to take them. These drugs help with inflammation, ease nausea, and

prevent migraines that I've had since I was a child. I also infuse a biologic drug, vedolizumab (Entyvio), into my port every 8 weeks.

Meanwhile, there are plenty of appointments to keep up with: I normally have blood work done once a month. When I'm on IV nutrition, a nurse comes to my house to do it weekly. I also see my internist every 3 months and my gastroenterologist twice a year. But lately I've had so many health problems that I've had to see my gastroenterologist every few weeks. I regularly see a neurologist and pain management specialist, too.

Seeking Balance

Trying to work a full-time job while managing my condition can be really intense. I don't think most people understand what it takes for me to be functional. Even health care professionals don't fully get it, which can be frustrating. When my gastroenterologist recently put me on TPN and clear fluids he told me to measure "ins and outs." In other words, he expects me to measure my fluid intake as well as collect and measure my urine and stool. That process keeps you homebound. I happen to be working from home now (due to COVID-

19), but sometimes I only have a 5 minute break between a class and a meeting.

I do feel lucky to have a great support network. I'm really close to my mom and we talk all the time. I wish we lived closer to my parents; I'm from upstate New York but live in Georgia now.

My husband and I have been married for 10 years, and we've been through a lot together. Like many couples our age, we'd love to start a family. I had a hysterectomy in my late 20s -- I had endometriosis and cysts that were adding scar tissue on top of what I already had from all the bowel surgeries. But we have embryos frozen and had started looking for a gestational carrier when COVID hit. I've been ready to be a mom for a while, so having to postpone it further has been devastating.

My husband and I have made all our financial decisions, including saving for IVF and a gestational carrier, with the assumption that I won't be a reliable source of income. After all, I was homebound for 2 years after finishing my master's. I decided to go back to work because I really enjoy it. If I'm going to be sick either way, I might as well be sick and do something I love.

There were times I was so sick that I thought I'd never have a career or a family. Now, with my husband and colleagues behind me, I'm fighting for both.

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Sources 
SOURCE:

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