

Caregiving: In Sickness and in Health

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My husband Patrick and I recently celebrated our third wedding anniversary. June 7, we will mark nine years since our first date. Patrick was the first, and only, man I dated following my Crohn's diagnosis. I hate to sound cliché, but when we met I had a feeling that he was "the one" so I looked for the right time to tell him what he was signing up for in regard to my health issues. I sought to find a delicate balance of telling him before either of us became too emotionally invested but waiting until we were close enough for me to share the intimate details of my life.

I wasn't overly worried that Patrick would walk away because he would have to take care of me or that I would be a burden. I wasn't looking or asking for his sympathy. But I needed to explain the rashes on my hands, arms, feet, and legs. I had to let him know not to take it personally when I didn't feel like going out. Most importantly, I wanted to make sure that he kept his bathroom well-stocked with toilet paper.

Telling him about my Crohn's wasn't too bad because at least inflammatory bowel disease (IBD) is treatable. The difficult part was telling him about my Crohn's-related primary sclerosing cholangitis. How do you tell someone you might start a life with that you don't know how long that life is going to last because you'll eventually need a liver transplant?

I don't remember when or how we first discussed my health issues. I may have been running a fever one weekend and told Patrick about an upcoming doctor's appointment. When I asked him what he remembered about learning that I was chronically ill, he said, "It was very sad. I was quite concerned because of the seriousness of your disease."

Patrick's job as a caregiver is relatively easy — for lack of a better word. Because I'm a control freak, I don't often ask for his help because I'm very particular about the way things are done. I only need him to accompany me to doctors' appointments when I'm not allowed to drive. So I'm often the one who explains my disease and treatments to him, which sometimes makes it difficult for him to be a proactive participant in my care.

"There may be things that I'm not aware of that I need to do because I don't have a lot of experience in caregiving," Patrick said. "But I'm very happy that you have outstanding medical guidance."



Patrick and me in my hospital room a week after my liver transplant in 2017.
(Photo by Patrick Olson)

Although Patrick is aware of my needs, my stubbornness and self-reliance often prevent him from being a caregiver. On multiple occasions, including immediately before my transplant, Patrick had urged me to call my doctor because I wasn't feeling well, but I shrugged him off because I'd already scheduled an appointment or bloodwork. He has earned the right to tell me, "I told you so," with all of the close calls, but he also understands that I know my body and my limits.

Patrick and I agree that his role as a caregiver is rarely a physical one. His caregiving doesn't differ from the usual expectations that couples in a relationship have of each other. I depend on him for emotional support when I'm frustrated about being sick or scared while waiting for test results. I rely on him for spiritual support to pray for and with me when I need to be uplifted. When I want to take a nap, he does the dishes or prepares dinner.

The one good thing — if you can call it that — about having a relationship that revolves around a chronic disease is that neither of us takes our love for granted. Saying what could be your final goodbyes and "I love yous" as you're wheeled away to an operating room makes you realize that every day, even the worst ones, should be appreciated because you live them together.

"Being a caregiver has brought us closer together because of what you have to go through," Patrick said. "You have to go through the internal, physical pain but I'm here to help you through it."

Much like the way I used to proofread his freelance sports articles before he submitted them, he proofs my columns before I send them to my editors. I may not need him to but his feedback gives me clarity and improves upon what I can accomplish on my own. The same goes for my health. Knowing that he's there to support me gives me the confidence and will to fight and survive.

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