



When the Patient Becomes the Caregiver

By Ilana Jacqueline

MY MOTHER AND I both suffer from primary immunodeficiency disease. My mother also has fibromyalgia that she chooses to treat without pain medication. For a woman who works in a high-stress job as a television producer, it's hard to see her hurting when I know she has so much weight on her shoulders.

She has always been a caretaker for me, and, now, as her parents age, she's become the main caretaker for them, too. Between my migraine spiral, my grandfather's lung cancer and my grandmother's colitis, my mother has spent almost the entirety of this month at someone's bedside in the emergency room. She's there to take the lead, tell the story and share our preferences when we are no longer able to voice them ourselves.

And her disease doesn't care. It's not like she gets to take a step back and say: "Whoa there, aching joints! Somebody else needs my attention!" She's at the mercy of her symptoms just as much as we all are at any inopportune moment.

I've often pondered the strength of caregivers. I know my new husband, RJ, loves me, but the fact that he can keep his cool when I roll over in the middle of the night and say it's time to go to the ER is something that's still hard to process. There are lots of events and activities I care about. There are parties I want to go to and friends I want to see, but if I'm knee-deep in a bad flare, even these fun times won't happen.

So, how do patient-caregivers make moments of incredible support happen when someone else is in need?

On Saturday night, RJ and I went to a housewarming party for one of our old friends. We hadn't seen most of our social circle since we got back from our

honeymoon. We spent three hours (about an hour longer than I usually last at parties) catching up. When we finally got in the car to leave, my body felt so weighted and exhausted, I felt like I might just sink through the leather seat. It had been a stressful touch-and-go day all around. My mom and grandfather had been monitoring my grandmother, who was in critical condition at the hospital. We had wanted to stop by before the party, but were told to just come in the morning.

was the end. She wasn't going to make it through the night.

And I felt so grateful to be in this moment. There was incredible grief, but my tears were for the realization that if I had even stopped to think about how bad my body hurt after that day, I might not have come in the middle of the night. I might have waited until the morning and lost my chance to say goodbye.

I leaned on my husband as my own fatigue hit while we were waiting, watching over her. I knew that we could stay as

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When we got home around midnight, I was lying on my couch thinking all I wanted to do was jump in the bath, cozy up and go to bed. Instead, my phone rang. I knew immediately that it was going to be bad news and, without hesitation, we were out the door and in the car, begging to catch every green light on our way to the hospital.

My husband parked while my stepdad met me out in front of the emergency room. The two of us rushed through the hallways, my heart pounding. There was no exhaustion anymore, no pain. Just someone I loved waiting for me to come say goodbye.

When we got to my grandmother's room, I wasn't surprised to see my mother already there and holding her hand. I went to her other side and took her hand. You could tell just by her eyes that this

long as we needed to, because he would take care of getting me home safely.

My stepdad took care of my mother that night. And all of us (including my uncle who had flown down in the nick of time) were there to support my grandfather — and each other. There is no secret to the willpower of withstanding our own pain as patient-caregivers; it's a simple explanation: We all rely on someone to take care of us, till the very end. ■



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