



I Wish I Could Tell My Friends

By Ilana Jacqueline

HERE'S WHAT I wish I could tell my friends: I have every excuse in the world why you aren't there for me.

I'm sick too often. I'm sick, and I'm too quiet about it. I'm sick, and I don't make a "big deal" out of being in the hospital. I'm sick, but my husband and mom will be there for me. I'm sick, but this is just part of my life. And, you don't have to hold my hand through every single day of it; that isn't what friends are for.

At least, those were the excuses I came up with during a particularly long hospital stay after a very grueling surgery. I waited for my friends to call or visit; I would have been moved if they'd even texted. But there was radio silence.

I was stunned, but told myself: I'm OK. I don't need their support. They have busy lives. It's a busy week. I can't just expect them to drop everything and acknowledge that I'm struggling a little bit here. Can I?

I'm very careful to not step over that line. I don't want to be that girl who always talks only about her disease. Of course, with most of my health-writing career based on my disease, it's hard not to be that girl. But when I'm with my friends, I have an open ear, and I try hard to not make the whole conversation about how this huge monster of a disease sometimes clouds my entire universe.

I had to work this out in my head. Did they not notice? Or did they just not care that I was in the hospital having major surgery? Were they uncomfortable checking in on me, or had too much happening during that week, or what? What?

In the end, all that really mattered was that by the time I was home and well-rested enough to think about it, all I could think was: "Wow, I have so many meaningless friendships."

I was hurt. I didn't want to get angry, yell at them or be passive-aggressive. I just wanted some space to digest the idea that people who I had hung out with for years just weren't as close to me as I thought they were.

I turned to my sister who'd recently gone through something similar after her fiancé was diagnosed with pancreatic cancer. Some of their friends just seemed to disappear in the moment. They didn't reach out at all. It was baffling. She remembered feeling like she was speaking to them in another language. They would change the subject.

You can't force someone to care, she said to me. You can't shake someone by the shoulders until some nugget of knowledge and empathy comes tumbling out of their mouths. You can't "will" someone to show up in the surgical waiting room or be there by your bedside when you wake up in the hospital. You can't ask them to say the right thing or stand beside you silently until the worst of it is over.

There are moments during chronic illness that are unspeakably lonely. Really, unspeakably — like no one ever talks about them. The moments when you're deciding whether to go out for the night because you just aren't sure your body is going to let you. Or, when you want to be the one to get in your car in the middle of the night and bring the ice cream to a friend whose boyfriend has just broken up with her — but you can't, because you have no more energy after the day. All you can do is pick up the phone and hope it's enough. No one talks about that moment after an unsettling doctor's appointment when you're crying in your car and wish someone was there next to you making you laugh.



I don't have the answers. Give your friends the benefit of the doubt? Don't throw the baby out with the bathwater? Whittle down the list of people in your life to those who would show up to ask if this was a regular Tuesday crisis or a major medical meltdown? (And would slow down just long enough to check on you with either one, either way?)

All I know is that rare diseases come with the need for strong friendships. There's a quote from Brené Brown, a research professor and author, that reminds me what I'm looking for: "I'm looking for what I call my 'move the body' friends. I'm looking for the folks who are going to show up and wade through the deep with me."

While the water may never be shallow in a life with chronic illness, I know there must be people who strap on their fins and set out to swim. I'm going to be one of them for someone else, and I know, someday, I'll look around and feel the aid of friends who will be there to swim with me. Because even if you've been swimming these waters forever, it's better not to swim alone. ■



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