

Self-Advocacy



Are you kidding me? Another \$749 out-of-pocket... just for lab tests?

It was another unexpected medical bill, even more irritating than usual because I had called the lab before the test was done to clarify the cost. The lab had assured me I would pay no more than \$200, even if my insurance company failed to pick up the tab.

It was New Year's Eve, after 5 p.m., when I got the bill, so I had to wait until after the holiday for an explanation. Meanwhile I stewed. My deductible was met—it was the end of the year. I didn't even understand what the expensive lab test was. Even with Google and a medical degree (I'm a family doctor), I couldn't figure it out.

The day after the holiday, I called the lab. After providing all the requisite patient identifiers, I was told that, in fact, I could pay \$199.74 to settle up and close out the bill. I did not have to pay \$749.

Why? Who knows. Why, after all, did I get MS? Why can't I keep track of my keys and my phone?

My reaction to the much-reduced lab bill was equal parts relief and rage: relief because I didn't have to pay \$749, and rage because I never should have received that bill in the first place. What if I hadn't called the lab to ask about the cost ahead of time? What if I, or a caregiver, had just paid the \$749 bill? I can't imagine I would have been refunded for overpayment.

This affirmed what I've known all along, as a doctor and as a patient: I have to advocate for myself. I can't count on anyone else to do it for me. I have to assume, most of the time, that

my insurance **won't** cover the cost, that my medicine **won't** come on time.

Even with my proactive efforts to avoid disaster, I have had my medicine fail to show up as expected. My labs have gotten lost in transit to my doctor. I've been told my labs were normal when they weren't. I've been double-billed for an MRI and got so frustrated trying to resolve the situation that I double-paid. Nearly anyone with a chronic or serious health condition can relate.

Over my career as a physician for people without health insurance, I have learned to advocate for my patients. I know where to find discounted medicine, how to track down lost hospital records, how to save money on x-rays. I know how to pester specialists to see patients for free or get them in for an urgent appointment on a too-busy day.

And since my MS diagnosis in 2009, I have had to kick it up a notch.

Self-advocacy is crucial to staying as healthy as possible. For those of us living with MS, we have to prepare well for our medical visits, keep track of schedules for labs and MRIs, and waste time calling and listening to bad music on hold, before fighting with insurance companies to get coverage for our "specialty" medications.

And it doesn't stop with medical care. We have to be vigilant to protect our sleep schedule, our energy level, our exercise time. We have to insist on three healthy meals a day.

I have had patients afraid to stand up for themselves, embarrassed to admit they can't afford a medicine or to tell me when they have side effects. Sometimes they go to the pharmacy only to leave and never return because the prescription isn't ready, the line is too long, or the cost is too high. And their health suffers.

My fellow MS warriors, don't be that patient.

Our healthcare system is broken, confusing and inefficient. It is not friendly or person-centered. But by asking lots of questions, prioritizing our medical appointments and self-care, identifying and advocating to get our needs met, we can overcome obstacles and lead our best lives possible.