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Letter to the Editor

This is NOT Normal



I am an abdominal radiologist. I graduated radiology residency in 2005 and then did a 1-year fellowship. In addition to reading computed tomography (CT) scans, magnetic resonance images (MRIs), and ultrasounds, I performed and interpreted fluoroscopic examinations and did a fair number of image-guided biopsies.

I then moved across the country and started a new job. I had a 3-year-old daughter and 1-year-old twin boys.

One day, about a year and a half after I moved, I was sitting in the reading room reading a CT scan, when I bent over in my chair to put something in my bag that was on the floor right beside me. Then, when I sat up, I instantly got a terrible headache. It lasted for about 15 seconds. Weird. But, I didn't pay it much mind.

Then, a few days later, I was sitting in my office to interview a prospective medical student. When I stood up after the 30-minute interview, I instantly got a searing headache and could hardly see because almost all I could see were pulsating red worms, retinal vessels. I didn't want to alarm the applicant, who was probably already very nervous, so I somehow managed to walk her back to the admissions office and acted as if everything were fine. I made it back to my office, still with that headache, and called for a neurology appointment.

A couple of days later, I had my first (of what would become many) MRIs. A few things happened during that appointment that raised my suspicions that something was very wrong with me. First, the technologist came into the scan room partly through the test to give me contrast. Even though I am an abdominal radiologist, I remembered from my residency that we didn't really do that for neuroimaging unless we saw something worrisome. Second, the technologist, excellent and very experienced, initially missed my vein (he must have been so nervous—I'm usually a pretty easy stick). Third, the neurologist who ordered for the MRI was waiting for me in the hallway after the scan was done (alerted by the neuroradiologist to intercept me before I looked at the images myself, I later learned).

I had a mass, a big one, in my brainstem, and it had grown so much as to obstruct the flow of cerebrospinal fluid.

Within days of my initial headache, I had an urgent craniotomy, followed by intensive care unit (ICU), the regular hospital floor, inpatient, and outpatient rehabilitation, in different orders,

sometimes multiple times. When it was all over, I had been away from work for a year.

During that year, I learned a lot of things. Two of the biggest ones may be of interest to you.

First of all, I had a complete and sudden lack of control over my own life. Literally overnight, I went from being a highly functioning person to needing help with *everything*. People had to tell me when it was time to eat, time to walk around (when I could), time to brush my hair, and so forth. I was told when I was allowed to get up and take a shower (which I needed help with for *months*), what I was supposed to eat, and when it was time to go to bed. I was sick and was so focused on learning how to walk, drink without sputtering, and dealing with severe postoperative balance issues (pretty common after someone has fooled around with your brainstem) that I didn't have the mental energy for anything else. Every once in a while, I would sense that people who were taking care of me would get impatient with me, which made me feel *awful*. I was painfully aware of how much care I, all of the sudden, needed and how pitiful and helpless I was. I was already so frustrated with myself, and I really didn't need to be a source of frustration to others. But, much more often than not, people would express their frustration *for* (not at) me. That was very helpful and leads me to the second thing.

This was not normal, at least not for me. I think, in an attempt to not make me feel bad, people would act very nonchalant when I would stumble when I walked, needed help feeding myself, or tried to sit down and not partly miss the chair. "It's ok. You're ok", they would say. And all I could think was, "It's not ok! I'm not okay! I used to be able to do this without even thinking!" I remember an intern when I was in the ICU for the first time, right after surgery. I was acutely, severely hypertensive. No one knew why. The intern, very unexcitedly, said, "That's ok, we have medication that can take care of that", and started a nitro drip. But, it wasn't "ok". I had never had blood pressure problems before, even a few hours before. I think we try so hard to normalize things because we want to calm our patients, but it is assumed that whatever might be happening to the patient is "normal" and "ok". It isn't. It would have been so much better had that intern said "Hmmm. I share your concern; I don't know why your blood pressure is high. I'll try to figure it out. But, in the meantime, let me give you a medicine that will bring your blood pressure down, regardless of what is elevating it." Not knowing is ok, but pretending like this is no big deal can be unintentionally dismissive.

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Fast-forward 8 years, I am back to work and loads better. But, I had to (and, thankfully, I was able to) drastically change both my home and work life and activities. For example, I have persistent fine motor skill problems, which affects mostly everything I do. As a result, I no longer perform biopsies, and writing by hand is extremely difficult. There are loads of other things as well. It's a constant reminder.

But, I am very fortunate. Many others, sadly, do not come out the other side. I did. And I learned that little things that we do or say to patients have an undeniable effect on them. There are real

people, and they're probably not used to whatever is happening to them, even if it's pretty ordinary for us.

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