

When a horrifying diagnosis is a relief

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I had just finished reading my essay aloud to the memoir class, my knees knocking under the Formica desk, the scarred wood chair growing warm beneath my thighs. My face burned as if I sat naked in a sauna. I felt naked, for what I had just shared. It was the story of the morning my 11-year old son received a diagnosis of brain tumor. More specifically, as I had already learned from our memoir instructor to “keep the story small,” the essay was about my reaction to the news.

As I looked up from my trembling pages, there was stunned silence. Some eyes avoided mine, some telegraphed concern, their baby blues or browns or hazels helping to calm my racing heart. From across the room, where the day’s last rays set afire her auburn hair, Marion, our resident authority, leaned forward. Absent-mindedly tapping her pencil on her chipped Formica, she said “Good job.” I knew from previous sessions that she meant, “Good job in getting that down on paper,” not “Good job on the wonderful piece that belongs in *The New Yorker*.”

Matthew was fourteen, three years after being diagnosed, when I sat there in class feeling so exposed. Prior to my memoir class, the most creative thing I'd written in years was "Mommy Goes on a Trip" in crayon on construction paper when Matthew was about three. Since then, I'd written plenty—year-end reports, grant applications, family Christmas letters. *How hard could it be to write my story?* I thought as I registered for the writing class. I soon got the answer in my strained wrists and bruised ego.

Marion invited feedback from the class. One older man, a deacon as I recall, shook his white head of hair back and forth as he listened to the other comments. When his turn came, he shrugged his sweater vested shoulders, looking over his bi-focals at me.

"I just don't get it," he said. "I don't get why you'd feel good about that diagnosis."

Ouch.

If a soul could recoil in shame like a grade-schooler's knuckles rapped by a ruler, mine did. I felt my face turn from red to crimson—so hot that at any moment, it seemed, I could burst into flames. Then the well of tears sloshing around behind my eyes would give way, effectively putting me out.

Other than my flushed face, however, I gave no outward sign of discomfort. I nodded politely, scribbled something on my paper so as to avoid the deacon's eyes, and prayed that my thumping heart was not visible. Marion rescued me by again complimenting my efforts and encouraging me to "go back, slow it down, tell us more." I maintained control through the rest of the readings, but as soon as class ended, I slunk away and licked my wounds at home with chocolate and chardonnay.

I accepted responsibility for not being clear in my writing. If a reader didn't get it, they didn't get it. It wasn't the reader's job to figure it out, it was the writer's job to make it apparent. So I tried again, sitting in front of my computer day after day, asking the ceiling, *How do I explain my reaction?*

Relief was the feeling the deacon failed to understand. In the face of a horrible diagnosis, relief defies logic. Dread is what a reader expects, a predictable response when brain tumor enters the family lexicon. I felt both—relief *and* dread. They bombarded me simultaneously, locked together like opposite poles of two magnets. In order to explain my relief, I had to pry it loose, examine it, understand it myself before I could lay it out for a reader in simple terms. Finally, after more thinking than writing, it began to make sense.

I felt relief for two reasons. First, my son's diagnosis wasn't fatal. I didn't know that at first, when the radiologist pointed to an MRI image of Matthew's distorted brain and said, "We found a growth." But before my mind could make sense of the image or the words or conceive of a future or lack thereof, the radiologist added four life-giving words: "not malignant" and "not serious." While I was still in shock, before I could feel *anything*, as the

words ricocheted around the room, relief was already present, already latched on to dread, already curtailing dread's energy. Had the news been different, had I been given no prognosis or a poor one, there would be no relief, no magnets, no confusion about perceived feelings. I may have chosen not to write that essay, but if I had, it would be easy to explain the anvil of dread on my heart. What I received with the words "not serious" was a future with my son and a complex story to tell.

The other reason for my relief was that Matthew's diagnosis was a long time in coming. Had it been sudden, dropped in my lap like a forkful of apple pie that didn't make it to my mouth, there would be nothing to be relieved *about*. One day your child is fine, the next day— *Bam!*—they're not fine. Malignant or serious or neither, there's no *Phew* moment there.

Relief comes when the diagnosis sounds better than the life you've been living. For three years, mine was a guilt-ridden life full of confusion, frustration, exhaustion and hopelessness as Matthew experienced increasingly severe tics, clumsiness, forgetfulness, and withdrawal. His behavior was so challenging at times, I believed I had failed as a mom. His behavior was so unusual at other times, I wondered how he would get through life. For the first two years, when I asked "What's wrong with my child?" Matthew's teachers, his pediatrician, my family, even my loving husband answered "nothing" or "nothing to worry about." As they shook their heads and shrugged their shoulders, our smart "Little Einstein," my fast-footed "gazelle," slowly deteriorated, his body and mind gradually stripping him of our affectionate nicknames.

In the last of the three years, when I started to think I was crazy, and maybe I was a little crazy by then, when my husband finally realized "nothing" was not the answer, when a slew of doctors threw terms like Tourette syndrome and muscular dystrophy and schizophrenia against their diagnostic dartboards, and finally we got an answer which was not fatal, then, yes, it felt good and I was relieved. I will own that and sing it to the heavens and not be shamed.

There's a relevant saying that I thought of often in the days following our D-day: "Until you admit there's a problem, you can't solve the problem." A diagnosis admits there's a problem. It gives a name to whatever is going on and going wrong. It says, "This (fill in the blank) is what the problem was all along." With that admission, a discussion can begin about how to solve the problem.

Sadly, "solving the problem" often is not synonymous with "being cured." In our case, Matthew's tumor was inoperable, attached to his brain stem, too deep within convoluted tissue to reach. The hydrocephalus—the fluid trapped by the tumor in his brain's ventricles—could be drained through a surgically created pathway, but it would happen drop by drop, year by year. We were all stuck with his injured brain; *that* could not be undone. The problem solved by the diagnosis was the self-doubt and worry and angst and

unmanageability of life that happens when you don't know what the hell is happening or what you're dealing with, or *if* you're dealing with anything other than dismissive doctors. The solution for us was not a cure or a quick fix, but rather a way forward to living our best, if imperfect, life. If that's as close to solving a problem as I can get, I'll take it.

I've since discovered that I'm not alone. I've read many stories of parents and patients who express relief at finding out they or their children have ADHD, heart disease, autism, MS, bipolar disorder, and other diagnoses, after years of wondering what was wrong and often blaming themselves for being less strong/capable/smart/together than their healthier counterparts. Knowing is often better than not knowing. Sometimes it's that simple.

On D-day, when I realized that we finally had identified the problem to which there was a solution, when I looked at my precious child laying on a gurney, I regained hope. When you've lost hope, getting it back is a damn big relief.

The three years of an unmanageable life, the magnets, the hope— *that's* what I had not communicated in my essay. *That's* what would have made my relief believable. I didn't try again, not in that class, not that particular memory. But I kept working at it, and the story evolved over two decades. "Not serious" turned out to be misleading, as Matthew struggled for years to reliably remember that it was Tuesday, not Thursday, and that Nana and Grandpop visited last month, not last week. But he somehow graduated from high school and then college (in four years!) and moved out on his own. He sold mattresses and insurance and men's clothes, or tried to. He delivered phone books and furniture and census surveys, or tried to. He was let go from more jobs than he quit.

And then, gradually, things started to click, each cog of every gear in his brain nudged the next one so the machine that is Matthew began to purr. He never recovered quite the level of his former Einstein or gazelle talents, but today, at 31, he's smart, healthy, and well-employed. He's also compassionate, insightful, and resourceful, gifts he may have failed to realize in a tumor-free life. And he's writing, too, in sensitive and stark prose, his own story about those early days.

Talk about relief.

I continue to hone my craft, taking writing classes, joining writer's forums, sharing bits and pieces of my story and putting the final touches on my memoir. I don't recall the name of the deacon in my memoir class so long ago. I don't remember much about him. But I hope someday he finds my story and Matthew's. I hope he'll shake his white head up and down this time, look over his bi-focals into the past, and say to himself, "Now I get it."

Karen DeBonis started her writing journey twenty years ago when her son was diagnosed with a brain tumor. Then she put the writing aside for ten years, as living in

the present with her son's recovery left no time or energy for writing about the past. For another ten years, as her son continued to recover and Karen rebuilt her career, her writing remained locked away in ancient computer files and a dusty box in the attic. Now, it's time to finish what she started. Karen writes about personal growth, self-acceptance, and life lessons, all of them major themes in her memoir, in progress. She can be found at www.karendebonis.com, on Facebook at www.facebook.com/KDeBoniswriter/ and on Twitter @KarenDeBonis