Not Knowing

Category: Stories
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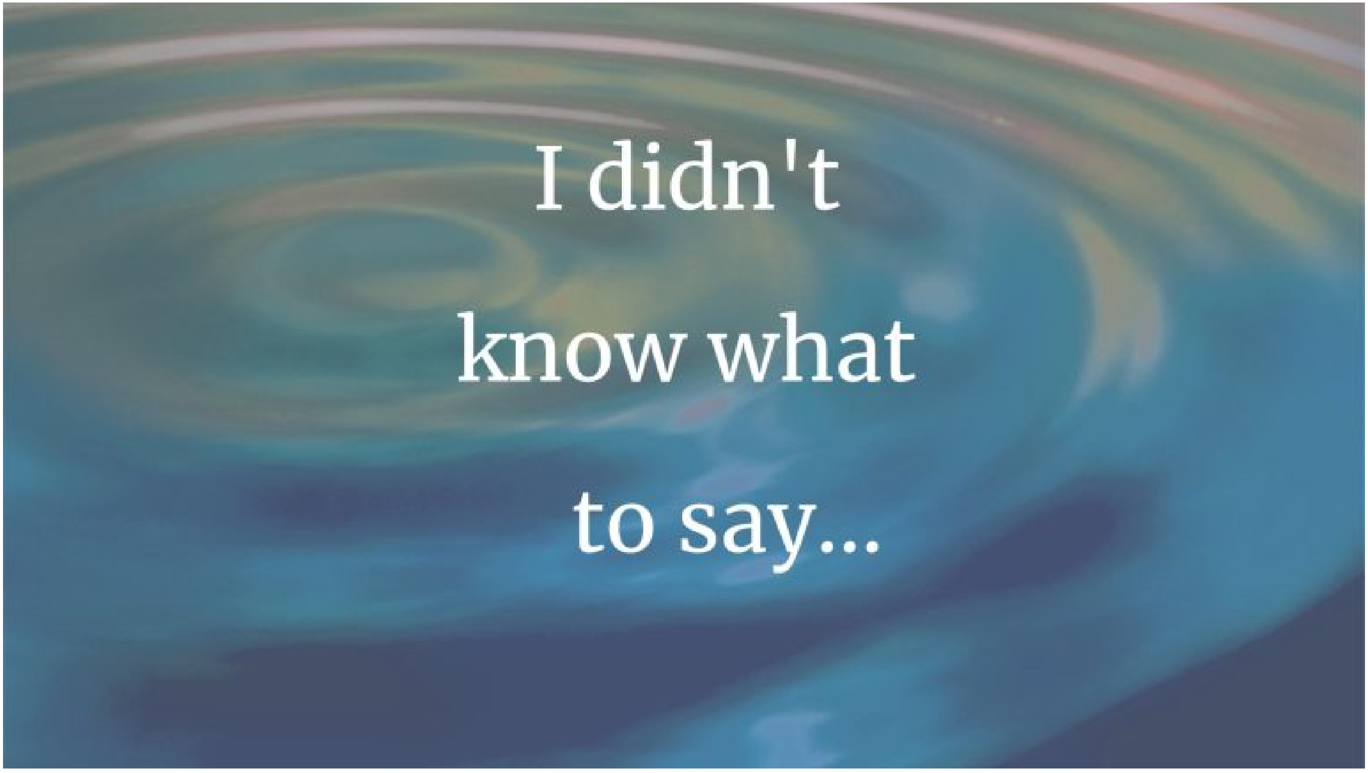

A few days after I’d rotated off the adolescent ward at the university hospital where I was a second-year pediatric resident, I stopped in at Billy’s room to see how he was doing. He was pale, with a few fresh bruises below the sleeves of his hospital gown, but his big brown eyes brightened when he saw me.

“Where’ve you been?” he asked.

“She had to go to work on another ward,” his mom said, rubbing his forearm gently. “I told you that, remember?”

Once I’d settled into the orange plastic chair near his parents in their scarred and sagging hospital recliners, Billy’s dad said, “You missed the excitement the other day. Billy had a seizure. Good thing the bed rails were up, or he’d have fallen clean out of bed!”

Billy’s and his parents’ chuckles soon turned to laughter. Taken aback by their macabre sense of humor, I was glad I’d missed this event—likely an indicator of brain metastases—but also touched that they could laugh about it.

Billy, sixteen, was from the rural western part of the state. His people were farmers, solid and earthy and pragmatic. He’d carried a diagnosis of acute myelogenous leukemia, or AML, for two-and-a-half years.

While the five-year survival rate among children and teens with this malignancy has increased since Billy’s diagnosis in the 1970s, it has always been significantly less than that of acute lymphocytic leukemia (ALL)—the “good” kind of leukemia. In 1979, when I was Billy’s doctor, his relatively long survival time made him an outlier.

I chatted with Billy and his parents for about twenty minutes, and his mom accompanied me into the hallway after I’d said goodbye and returned his bashful wave.

“Thanks for coming by,” she said. “I know Billy appreciated your visit.”

I beat a hasty retreat, furtively wiping away a tear. There was a kind of luminous innocence about Billy that had endeared him to me. His uncomplaining perseverance in the face of his disease filled me with a mixture of admiration and heartbreak.

During my time on the adolescent ward, whenever there was a lull in the nighttime admissions, I’d head to Billy’s room and watch *Wide World of Sports* or *The Wonderful World of Disney* with him and his parents. Sometimes he was alone—like the night he told me, with tears in his eyes, that it hurt to swallow.

When I explained that he probably had thrush, a common and treatable side effect of chemotherapy, he nodded. I was glad that my explanation seemed to help.

Then he said, “Do you think I’m going to die?”

I didn’t know what to say. Billy had been in the hospital for several weeks, after many previous stays and two-and-a-half years’ worth of outpatient visits for chemotherapy and its attendant woes: low blood counts, infections and potential infections, ailments of just about every organ system. I’d taken care of several kids with cancer in medical school, as well as in my residency; and six years earlier, I’d watched the inexorable progress of my own mother’s cancer. I knew the drill. I was pretty sure that this boy who’d crept into my heart was getting close to the end of the line. How could I tell him that?

I fell back on lame doctor-speak, the refuge of any medical professional who’s ever recoiled from telling a patient the unvarnished truth.

“We’re doing everything we can for you, Billy,” I said.

It was so much easier when his questions had to do with things like AML or thrush, I reflected later. The granular, detailed questions I could handle; the big, existential ones, not so much. I’d skittered away from that one like a startled backyard deer.

One night, not long after this incident, Billy’s IV came out during a transfusion. His platelet count was dangerously low, and he was actively bleeding from his nose and into his urine and his GI tract. This usually quiet boy was crying and flailing, wild with pain and fear. My attempts to restart his IV failed, and after a few tries, I was almost as agitated as he was.

“Nothing is going to work!” he shouted, yanking his arm away.

I slipped out into the hallway and paged the third-year resident, who held me while I sobbed, then went in and got Billy’s IV restarted.

That was one of the worst nights of my residency.

In the decades since Billy was my patient, I’ve thought about him often, wondering what would have happened if I could have opened up to his question on that quiet night. What if I’d been able to listen deeply, to give him the space to express his fear and grief, to accompany him into that terrifying, uncharted territory, the unknowability of death?

I was twenty-eight years old then, still an apprentice. Did I think Billy was going to die of his AML? Yes, for sure. Did I have any idea when? Soon, but who could say exactly? And there was also that unspoken, unanswerable question that haunts us all when we’re confronted with the mystery of the *when* and *how* of death—particularly when the dying patient is young:

Why?

It took me years to learn that the thing Billy needed most from me that night was not medical explanations, maybe not even a direct answer to his question, but just my presence—my being there with him, bearing witness to his suffering. As a young physician, though, I’d had it drilled into me that I was supposed to have *answers*, dammit.

Eventually I would learn that, beyond certain basics of physiology, “answers” in medicine—as in most of human existence—are never complete, and often ephemeral, even illusory.

Shortly after my last visit with Billy in his hospital room, I went on the first two-week vacation I’d had since medical school. Billy died sometime after I got back. I never saw him again. I’m not sure how I learned that Billy had died—whether someone took me aside to break the news, knowing how much I cared for him, or whether I heard it in passing from a colleague. I don’t remember whether I cried.

Billy, I’m sorry I wasn’t fully there for you in the way you needed me to be. But I thank you for what you taught me: about resilience; about presence; and about being there with each other in that place of not knowing—the place where our most momentous experiences take place.