Kids Always Know

Category: Stories
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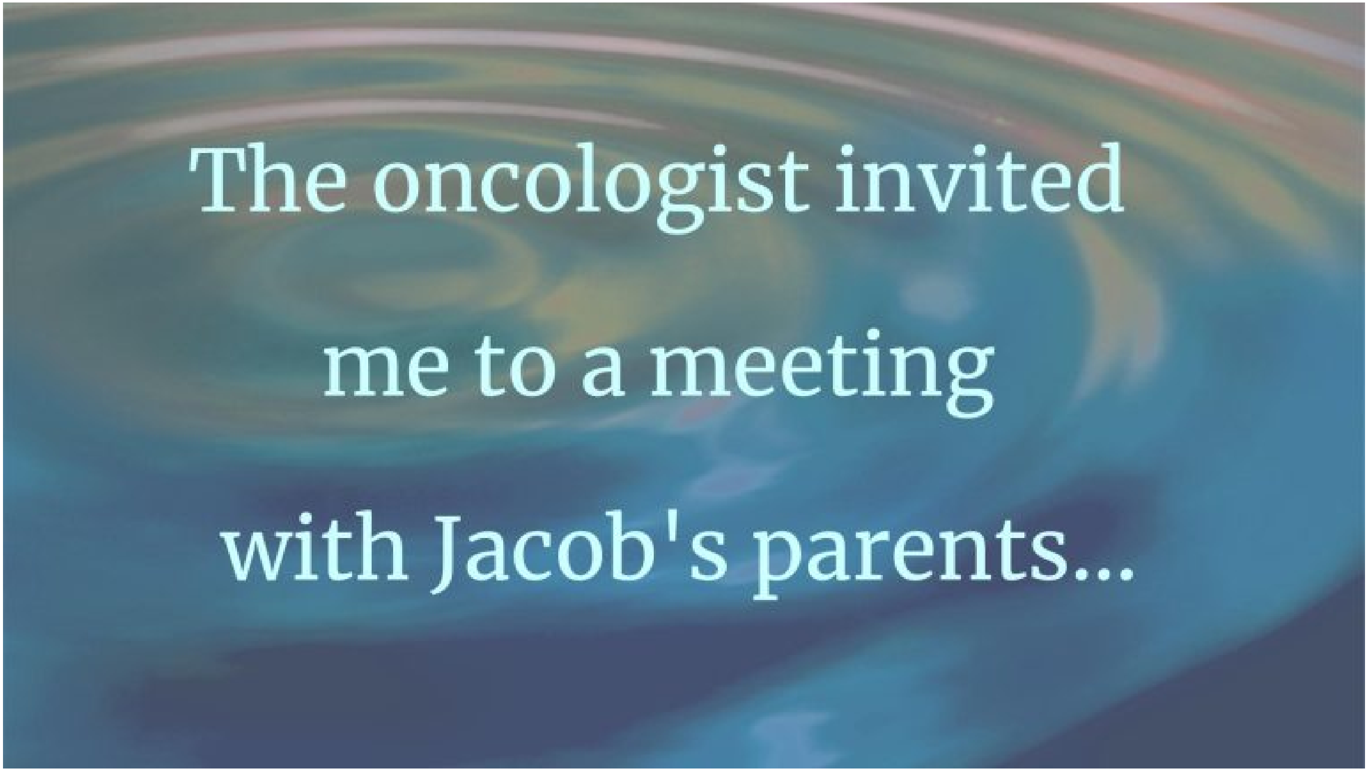

This is a story about failures. First, it's about my inability as a pediatric hospice physician to do the *one most important job* in this tender space. Second, it's about well-meaning, loving parents' inability to do *their part* in that job.

Jacob was a smart, funny, elementary-age kid, great with Legos. He had two doting parents and a younger sister. A close, loving family with a strong religious faith. They also had a huge circle of friends and family members who provided meals, helped with Jacob's sister and came over to support his mom.

Jacob had a malignant tumor in his lower brainstem and upper spine. His parents took turns staying with him in the hospital, where Jacob masterfully constructed Lego projects on the days when he was feeling good. His body tolerated the aggressive chemotherapy treatment pretty well, but the tumor continued to grow.

When there were no other chemotherapy agents to offer, the oncologist invited me to attend a meeting with Jacob's parents. He advised them that there would be no benefit to further office visits, blood work, scans or chemotherapy. It was time to consider home hospice care.

“What does Jacob understand about his cancer?” I asked.

“We told him at the beginning that the medicine would make it go away,” his mother said.

I counted to twenty in my head, remembering the countless times I’d heard parents offer half-truths, lies or ill-advised promises to disguise the daunting reality of their child’s illness.

“What will you tell him now?” I pressed.

“We told him he’s going home. The doctor will call us when it’s time for chemo again.”

“The hospice team and I will be making home visits,” I said. “Over the next few weeks, I’ll try to help you find the words to tell him the truth. We’ll bring you some books you can read to Jacob and his sister. Meanwhile, I’d encourage you to be open to any questions he asks about what’s going on. Kids always know more than we think they do.”

I described the hospice team—nurses, a social worker, a chaplain—who would support Jacob and his family as his disease progressed, and briefly covered the basic information about emergency care and using medications to manage Jacob’s symptoms. His parents seemed stunned; they had no questions.

Over several months, Jacob grew weaker and weaker. Initially he could walk with assistance, until he couldn’t. His mother would carry him to the couch, where he would play games and watch movies on his iPad.

During my home visits, she never left me alone with Jacob. Early on, when I asked for a few minutes with him privately, she said, “Oh, I’ll just be over here folding laundry. You can talk with him.”

She never left the room. When I left that day, I asked her why she was reluctant to leave me alone with him.

Quietly, looking down at the floor, she said, “I’m afraid you’ll talk about dying.”

“I would never do that without your permission,” I assured her. But she always hovered nearby.

Jacob answered my questions with superficial answers, seeming to know instinctively what his mother wanted to hear. I couldn’t develop a closer relationship with him, because his mother inserted herself into our conversations. As soon as I stepped into the foyer, I had the impression that she was trying to shoo me out. Walking toward the den where Jacob was positioned on the couch, she would say things like, “He’s been great! Eating well, no pain, no issues at all.” This report, for a child progressively paralyzed. No wonder Jacob’s answers parroted his mother’s. She did the same with our nurses.

At my last visit, Jacob was paralyzed from the neck down and needed his mother nearby even to scratch his nose. Now all he could do was watch movies on his iPad all day long. His voice had grown shakier and softer, until he could hardly speak. This change alarmed me; I was afraid he would suffocate as his tumor infiltrated the brainstem’s breathing center—an unnecessarily traumatic death.

One weekend, the family traveled hundreds of miles to a special service for healing, where the priest sprinkled holy water on Jacob’s head and said prayers in Spanish.

“What did Jacob think of that?” I asked his mother.

“He didn’t understand a lot of the service, but he liked the trip. Actually, he slept most of the way there and back.”

And still his parents could not bring themselves to tell him he was dying.

“I’m afraid it’ll make him sad,” his mother said to me as we stood in the entry hall.

I looked back at Jacob lying on the couch.

“What do you imagine Jacob is thinking, now that he can’t move?” I asked. “Does he ever ask?”

“No,” she said. “He doesn’t ask. He used to ask when we were going to go back to the clinic, but he doesn’t ask anymore.”

That’s because he knows already, I thought.

She tried to hold back her tears, her fists tightly clenched at her side. “Sometimes he wakes up crying at night, but he just says he’s having a bad dream. I just can’t tell him.”

I stood there in the entryway, one hand on the doorknob, shifting uncertainly, feeling the pressure to get this right.

“You know, I remember taking care of a child one time whose mother talked with her about her death in such an amazing, gentle way,” I said tentatively. “This mom told her daughter that life is like a marathon, a very long race. She told the little girl that she, the child, would finish the race before her parents or her sister—and that when she got to the finish line, she should just wait there for her family, because they would join her soon, and then they’d all be together again. I found this mom’s explanation so comforting myself: I wonder if something similar would be helpful for Jacob?”

She nodded, tearfully, but said nothing. I was under no illusion I had given her the courage to introduce the topic.

“I know this is hard for you—I can understand how sad it will be for you and your husband to have this conversation with Jacob,” I said, trying not to let my irritation show. “And I’m sure he will be sad to imagine leaving you. But he *needs* you to be at your strongest right now—he needs to know the truth, so you can answer his questions and calm his fears.”

To help Jacob’s parents talk to him about his impending death, our social worker, Cara, brought books and scripts that other families had found helpful. She offered to help them practice the conversation. But they never did tell Jacob what was happening.

Jacob died about three weeks after my last visit.

When Jacob's hospice nurse called one morning to tell me he had died, she was on her way to the home to pronounce the time of death. Neither of us was surprised, of course; his nurse had visited the home every day for the last week. Still, something felt unusually heavy about the news.

I was sitting at my desk in the hospital when she called. For the next half-hour, I did not move. My breath slowed, and I held both hands wrapped around my coffee mug as replays of the conversations I'd had with Jacob and his parents scrolled by in my head.

I felt so, so sad for Jacob. How lonely and isolated he must have felt. And scared. I wonder what he thought about at nighttime. I wonder if he ever had visions of family members who went before. I wonder if he ever had dreams that gave him comfort—dreams of floating on a cloud, running and playing. *Of course* he knew what was happening to his body, but he also knew that his parents were not open to talking about it.

Jacob's story has haunted me for several years now. I feel like I failed him. I should have found a way to guide his parents more effectively. I should have been more persistent, more persuasive. And I wonder, *Did they tell Jacob they loved him? Every day? Or did they hold back on telling him how much they loved him, to keep him from "guessing" that he was dying? Do they have any regrets about what they said or didn't say?*

I think of Jacob every time a parent tells me they don't want to talk with their terminally ill child about death. I don't accept the excuse of waiting for miracles, or praying for the cure. I don't accept the excuse of not wanting to take away hope.

I remember how I felt when Jacob died, like I had failed him. I don't ever want to feel that way again.

And so, every time the issue comes up, I tell the parents that the child always knows what is happening to their body—that *not* telling them creates a distance between parents and child at the very time when the child needs their closeness, love and support the most.

I push harder, for Jacob.