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ON CHILDREN BLOOD, AND CANCER

I met you on a Monday

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I met you on a Monday. A few weeks earlier, you were giggling and smiling, with rosy cheeks and chubby thighs. Everyone was surprised at how well you were handling your chemotherapy. You were only a few months old. I imagine your mom would hold you and smile as you cooed and looked curiously around the room. You probably had multiple nicknames, each said to you in moments of endearment. "She is so cute," the doctors would say as they went in and out of your room. I am sure your mom dressed you in the prettiest clothes and accessories. You were her first.

But I met you on *that* Monday. The Monday you came to the pediatric intensive care unit with a belly the size of a small watermelon, firm and round. You had lines and tubes piercing your skin. Your cheeks were no longer rosy. You had emergency surgery that day. You came back to us with less tissue and more plastic, but you were stable.

I visited you on Tuesday. Your mom was cautiously optimistic but was nervous with every provider encounter. She asked me, "how is she in this moment, doctor?" And I responded, "Right now, she is doing well." You had a bag over your open abdomen and needed multiple transfusions, but you were breathing. You were alive.

I said goodbye to you on Wednesday. As I walked into the unit that morning, a makeshift operating room was being set up outside of your room. You no longer had blood flowing to your legs. Every part of your body was puffy, making you almost unrecognizable. As doctors and nurses were rushing in and out of your room, I went to sit with your mom, who was around the corner. "Did you just get here?" she asked. "Yes," I responded. She looked at me calmly and said, "This must be a hard way to start your day." Your mom was just as strong as you were. I sat next to her in awe on arguably the worst day of her life, the last day of your life. Somehow through it all, she was still thinking about others.

It did not take long for your mom to decide to stop the surgery. She did not want any more lines or tubes. She did not want any more machines keeping you alive. She just wanted you to be comfortable. I asked her about funeral arrangements and an autopsy. I attempted to reassure her that any of her decisions were the right decisions. "I wouldn't have put her through all of this had I known," she whispered. We just did not know. How did we not know?

I thought back to the reassurance I had given your mother as I stood next to you a day earlier: *right now, she is doing well*. Were you doing well? Did I provide too much hope of you living, making it harder for her to realize you were dying? Was I being unrealistic that you were actually doing well? Fifteen hours later, I could not use that word to describe you.

Your mom held you as the lines and tubes were removed. She cradled you in her arms as we slowly watched the monitor outside of your room. In your final rebellion against death, your heart kept beating for 20 more minutes. I waited. I watched. I listened to your mom's cries as tears rolled down my own face. Then you were gone. Your mom left the hospital and your room was emptied. It was scrubbed and mopped, waiting for the next patient. Your room was filled in less than 24 hours. It was no longer your room, but the room of another sick child.

Right now, she is doing well. What does "well" even mean? What did "well" mean for you? I have said it to parents in clinic—"your child has a viral illness and will be well in a few days." I have used it to describe the child with the fractured arm—"the arm will heal and will be well in no time." Should I have said those words to your family? You were not a child with a cold or a broken bone.

I met you on a Monday and said goodbye to you on a Wednesday. Since your death, people have asked me how I am doing. I have caught myself reflexively saying, "I'm doing well." And then I pause. Most often, I can continue each day as usual. I can go from patient room to patient room, continuing to give care. I can laugh and smile. But your death happened, and it profoundly changed me. In random moments, I'll start to cry when I think of your last few days and hours. My breath catches when I think of your mom holding you close. I feel my anxiety increase when I think about the fragility of my own loved ones. And then I wonder, *am I really well*?

But as I process your death, I have learned that being well is more than just a physical state of being. Wellness also encompasses our ability to process and reflect and experience. In less than 72 hours, you taught me about the resilience of young bodies and the fragility of life. You showed me that we are willing to give everything to a child for the hope of more time. You also taught me that sometimes the best care

we can provide is one that focuses on comfort instead of additional medicines and surgeries.

When I think of you, I mourn the life that you could have had. I also celebrate the joy that you have given others and am hopeful for the love you experienced yourself. And as I continue to reflect and process, I am learning that my definition of "well" is fluid. I have come to realize that the day I no longer connect with patients, feel joy, or experience sadness is the day I will be unwell. For all that you have given, shared, and taught me, I thank you.

CONFLICT OF INTEREST

The author declares that there is no conflict of interest.

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