

IN SICKNESS AND HEALTH

Medical Center Traffic

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In twenty years of working in busy medical centers, I had never gotten used to the crazy way people drive around hospitals. Patients and visiting family members seem preoccupied with everything but driving. They turn unpredictably as if on bumper-car rides at the State Fair. They seem cowed by the signs and branching roadways. Like most healthy employees, I would get irritated at having to watch out for them. It's easy to forget how intimidating a place a medical center is—not just the size and complexity of the buildings, but the fact that all of it represents serious illness. It was always lost on me that none of these people wanted to be near here, not even to visit, because it brought them closer to their worst fears of known and unknown medical dangers.

I was feeling particularly irritable on a glum, overcast, mid-February day. A light dusting of snow on the ground had made the drivers more erratic than ever. One came to

a full stop directly in front of me despite the lack of a stop sign. Another swerved toward me from the left in halting jerks and starts. I was already late for a meeting and there were probably no more parking spots left. I was also preoccupied with various worries. They were largely concerns about work—trying to meet colleagues' expectations, deadline pressures, too many commitments. At the back of my mind, pushed mostly out of consciousness, lurked vague thoughts about my three-and-a-half-year-old son Evan's health problems.

Weeks before, we had sought medical attention for him because he seemed to tire so quickly and had more than the usual childhood quotient of colds and viral illnesses. He had gotten to the point where he seemed sick all the time. After routine causes had been ruled out, we had been referred to Dr. Emma Baines, a diligent and meticulous pediatric gastroenterologist. She had recently discovered through ultrasounds and CT scans that Evan had an enlarged spleen and an irregular liver. My wife and I knew that a big spleen in a small kid is rarely a good thing but we didn't understand what it meant. Then Dr. Baines had taken what seemed like several quarts of our son's blood to test. Those results weren't due until next week; I wasn't expecting to hear from her

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yet and figured I could put aside my worries about them for a while. "A while" lasted until later that Friday.

At about 3:00 p.m., my secretary let me know that Dr. Baines had been trying to reach me. I immediately paged her from my office phone. Beating out an impromptu and inaccurate tempo with my fingers, a rude drum solo akin to "Inna Gadda da Vida," I nervously waited and waited. It was the wait of a type A personality trying to kill 90 seconds and failing. Finally, my private phone line rang.

"We have a diagnosis for your son's liver condition," she announced right away. Her voice was mannered, a bit formal, but friendly in a cautious, concerned way. I felt terrified to the point of nausea. In an incoherent moment just as she was about to reveal her findings, I found myself thinking, "Was the Academy Award like this for a nominee? 'And the winner is. . .'" Cut it out. Listen. Stop distracting yourself.

"He has alpha-1 antitrypsin deficiency."

I made a nervous, tentative laugh while thinking to myself, "Well, it's got a highly technical name I've never heard of." After a pause, I vocalized in a trembling voice the first question that had haunted my nights: "Will he need a liver biopsy?" Up until that point, a liver biopsy was my main fear—sticking a huge needle in my beautiful boy! I knew I wouldn't be able to handle that.

"I don't think so," she said. "The diagnosis is definitive. We won't need more tests at this point." I began to quietly thank God for sparing him. "There's no treatment," she added. I thought, "Okay, so it's self-limiting, like a developmental thing." I felt a surge of relief wash over me as I fantasized alleviation of this burden. I heaved deep breaths and my eyes began to tear. But then Dr. Baines said in a firm, quiet voice, "He will need a liver transplant. It's the only known cure."

As long as I live, I will never forget the feeling that hit me. The blood rushed to my head so quickly that I felt fire in my face, tingling along my neck, and a foreign noise

in my ears. I felt a kind of fear I'd never experienced—deep, visceral fear that cut through to the center of my body.

Silence.

If I had drunk lye, my stomach may have felt worse, but I don't think so. The surge of relief that had lasted less than ten seconds was now replaced by the urge to vomit.

Questions, questions. You're supposed to have questions at a time like this. Instead, I still had no way of absorbing the information she was giving me. The last I saw of my son, he was driving his tricycle at roughly 86 miles an hour through the basement in figure-eight loops. Liver transplant? The words had no home in my head. I don't think I even managed a gasp.

"I'm sure this must be devastating news to you," she said.

Well, not really because I haven't quite understood you yet. Then I began wondering aloud, "Could it all be a mistake? What are the sensitivities and specificities of the tests you used? The predictive values? What is guiding your clinical thinking? What are the possibilities you're wrong?" There—questions galore. Now we were getting somewhere. Nothing like a little medical research background to load me up with the right questions. My old friend denial had come to protect me like it had so many times before.

"If all goes well, Evan will be with you for many years to come," she intoned in reassuring, measured words.

I thought to myself, "Many years? How about, say, 150? Longer than I'll be around, for sure. Maybe forever."

"If you would like to come in and see me, you can bring your wife any time this afternoon." Dr. Baines' voice continued to be calm, reassuring, persistently sensible. It was beginning to annoy me that she was so stable. I started to need to get worked up.

I was still stuck on "... many years. . ." I had never given my son's death a second's thought.

I had run out of questions. I answered,

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"I'll be over as soon as I can speak with Julie."
I hung up and sat silently with my heart
racing, trying desperately to make sense out
of what I had just been told. My office was
quiet enough to make me acutely aware now
of my gasps for air. For a medical sub-
specialist to clear her schedule in order to
give us total priority to meet with her—that
worried me. This was both urgent and
important. I hated this invasion.

The call.

How do you relay this to the mother of
your son? Not well, it turned out, despite
my best efforts at composure. "Hi. I just
spoke with Dr. Baines and the news isn't
good." Heaving breaths. More tears. "She
says he has a rare liver dis—" To say the
words would be to acknowledge their truth.
I choked. "He's going to need a trans—" I
couldn't continue. I finally just said, "I'll be
right home to pick you up. Get a sitter. We
need to go to the hospital right now." I
cancelled all my afternoon appointments and
rushed out the door, leaving the staff confused
and a little upset.

Outside, the world was gray and lifeless,
one of those winter days when the cloud
ceiling seems to be about twenty feet. When
I arrived at our house, everything seemed
two-dimensional, a black-and-white
photograph of our home. Julie's complexion
was ashen, as was mine, I'm sure.

Our elderly baby-sitter/surrogate-
grandma Toni appeared. She knew
instinctively that it was a time when we
needed her to take over. "Go for as long as
you need to," she said. "I'll make sure
everything is okay. Leave it to me. Don't
worry about anything." It was good for us
that she was talking. I was numb. I had no
idea how I had driven home.

Evan?

Toni responded, "He's asleep. I'll take care
of him. He'll be okay. I won't tell him
anything." We drove back to the GI Clinic
in near silence, dreading the conversation to
come. What would be said? Why? We were
dazed, confused, and angry.

We walked the long hallway at Children's
Hospital. It was bustling with activity on a
late Friday afternoon. I caught myself
diverting my eyes from the wheelchair-
bound kids, the kids that have masks and
the parents with their own masks of worry
and uncertainty. I had walked by the sign
that said "Clinic G" a hundred times before
without caring what it was; suddenly, as we
crossed its threshold, it had meaning to me.
The nurse seated us in an exam room and
we silently stared at pictures of Bert and
Ernie painted on the wall. I think they were
intended to be comforting but they felt
intrusive, like everything else about this
unwanted event. I don't believe I'd ever felt
so uncomfortable in my life.

Emma Baines entered the room wearing
down-to-earth clothes—a gray cardigan
sweater over an oxford cloth blouse. She wore
no lab coat. Her gray-flecked hair had been
cropped to minimize the need for daily
attention. I had the sudden strange thought
that she reminded me of Miss Jane Hathaway
from "The Beverly Hillbillies," all prim and
proper but a decent sort. She was all
business except for her eyes: topaz-blue orbs
that sparkled through tired lids. She fixed
those topaz-blue eyes directly on us. The
crinkle of crow's feet suggested that she
must smile often, but not just now. Precision
was the rule at this moment and she went
to work.

"I know this must be devastating news
for you" she repeated.

"Is it?" said Julie. She, too, wasn't ready
at first to accept what we'd been told.

But Dr. Baines had been here before. She
became more animated, dropping her
clipboard to her lap and removing her half
lenses, allowing a slight smile to form. It was
a smile of hope. "If he does have a transplant,
the prognosis is extremely good. It's a true
cure—a miracle," she explained, "But I know
it's hard for you to hear that right now."

Julie broke. "You're telling me my baby
boy needs a new liver? Tell me—just how is
that a miracle?"

Dr. Baines used silence and a tilt of her head and body to the greatest effect I have ever seen. Her determined gaze met ours and, without speaking, spoke to us. It felt like she was with us, not against us. She joined with us against this unseen, unknown foe—a condition I had never even heard of one hour earlier. I sensed that we had a champion. She continued her explanations but I will admit to zoning out on many of the words. Something about “watchful waiting” injected a note of hope. But when she said, “these liver function test numbers will become very familiar to you,” I felt like I was being forced to join some cult against my will; I didn’t want to have to know about my son’s liver functions. I do remember her referring to her patients, not as “patients,” but as “my little friends.” Other aspects of the conversation are less clear in my memory. Mostly, she was planting ideas for us to ponder later in the hope of convincing us that we could get through this horrible crisis.

The ride home was a gray blur. The weekend was generally subdued—tearful conversations, a trip to the movies for our second viewing of *Toy Story*. We held Evan tightly during the entire film, clinging to his ever-enthusiastic form, rubbing his tummy in some clumsy gesture of attempted healing. Returning home, we turned our energies to more grief and processing. But we also found ourselves, oddly, in a preparatory mode: cleaning the basement, storing old books, moving furniture, doing tasks that had needed doing for some time. Our strength began to return through no effort of our own and every effort of divine intervention. We felt that God was with us and that gave us a sense of purpose, though we had no way of knowing what that purpose might be.

On Monday morning, I commuted to the medical center, knowing that I would have

to share the news of Evan’s situation with my friends and colleagues. More stomach pain. Could I hold myself together? How would they react?

Driving in silence, I realized after a while that I hadn’t turned on the radio. No tunes, no “Morning Edition.” While lost in thought, I hit the customary traffic jam at the Medical Center near Children’s Hospital, one block from my office. Children’s Hospital was now a looming reminder of our ordeal. Bewildered, anxious parents and patients were trying to follow the Medical Center maze of confusing signs and inexplicable roads. I recalled how often I had cursed the traffic in my own haste to arrive on time, having left home too late. Today was different. I finally figured out who was in those cars.

ENDNOTE

Evan Holloway received a liver transplant on February 24, 1997. After nine days postoperative recovery (second shortest in the history of Children’s Hospital of Wisconsin), he was sent back home with his Mom and Dad. That summer, he became ill with a serious opportunistic infection, and successfully battled his way through it. He was finally discharged from Children’s Hospital on Halloween night, 1997, dressed as Winnie the Pooh and sporting a Halloween bag on one arm and a peripherally inserted central line on the other. He’s declared he won’t go back to Children’s, and so far he’s kept his promise: He turned eleven this year and is as healthy as any kid in his neighborhood. His immune suppression is minimal, and he makes occasional visits to the clinic for blood work and an obligatory nod to his pediatric gastroenterologist. This piece is dedicated to his courage, and my enduring wonder at how much a father can learn from his son.

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