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NARRATIVE MATTERS



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How To Win The Doctor Lottery

Not every doctor-patient encounter is healing, and it can seem a game of chance. One patient explores what it takes to win.

BY DONNA JACKSON NAKAZAWA

When my son was five weeks old, he began to turn away from my breast even when hungry. He'd suck, then cry sharply, and twist away. I called the office of the pediatrician I'd chosen while pregnant, but she had no free appointments, so I saw another doctor in the practice instead. I'll call him Dr. Jones. He examined my son, told me he had "gas pains," and asked me, "Are you feeling anxious about being a good mom?"

The next day my son seemed better. Was I overly anxious, I asked myself?

Then my son projectile vomited across the bedroom. I strapped him in his car seat and headed back to the doctor. Dr. Jones asked his nurse to take me aside for a "mom heart-to-heart." Being a new mom is anxiety-inducing, the nurse said, adding, "What are you doing for you?" I burst into tears. They must have thought I was a postpartum hormonal time bomb.

The next morning when my son tried to breastfeed, he stopped and screamed in a way that resonated within my cells. That cell-shock sensation was something I'd felt only once before in my life.

Three decades earlier, at the age of

twelve, I'd stood at the side of my father's hospital bed after he'd undergone a bowel resection, a "routine" gastrointestinal surgery. Every grown-up had told me that my dad would be fine despite postoperative complications. But as I looked into my father's eyes that afternoon, I saw a depth of pain-laced love and the anticipation of loss reflected there. My earth tipped on its axis. I suddenly knew that despite what everyone was telling me, my father would not be fine.

That night, at the age of forty-two, my father died.

Racing To Save My Child

I arrived at the pediatrician's office on the third morning of my son's unexplained distress. As I began to explain why I was there, Dr. Jones interrupted me, gave me a handout on colic and a pat on the back, and ushered me out.

Just at that moment, my son's original doctor—the one I'd joined the practice to see—stepped out of another room and saw me standing in the hallway.

"Haven't I seen you here every day?" she asked. Her eyes were kind. I nodded, swallowing back tears.

"Let's see your baby." She extended her arms and laid my son on the exam table, gently palpating his abdomen. "Tell me about when you first felt something wasn't right? What else have you been noticing?"

She took a bottle of breast milk from my hands and offered it to my son. He sucked, turned beet red, and twisted away with a sob. "Does he do this on the breast, too?"

I nodded.

Then she uttered the words that would save my son's life. "I listen to my moms," she said. "Given what I'm observing, I'd like to get an abdominal sonogram."

"But they told me it's colic." I suddenly hoped Dr. Jones had been right.

"His abdomen seems distended and hard," she said. "It's a subtle finding, but it's there."

A few hours later, after the sonogram, the pediatrician held the hospital's re-

port. It suggested pyloric stenosis, a condition caused by a tight muscle that prevents food from exiting the stomach and entering the intestines. When that muscle becomes rigid, it resembles an olive.

"I don't find this definitive," she continued. "I've called a pediatric surgeon at Hopkins. He'll meet you at the ER. Pack what you'll need for the next week."

I held my son; his tired exhales warm and moist against my neck. "Johns Hopkins?" I asked. That was where my father had died.

She put her hand on my arm. "I know this is difficult. But I promise you, we will help your baby. We will get through this."

She handed me a slip of paper. "Here's my cell. Call when you've arrived."

I held the paper like a talisman.

Later that afternoon, the Hopkins surgeon examined my son, rubbing his thumb over his belly, looking for the swollen muscle the local hospital said they'd seen. "Pyloric stenosis my eye!" he nearly roared. "There's no olive here!"

The new tests he wanted to run seemed invasive, and our pediatrician called to reassure my husband and me. "Please, trust us with your baby," she said. "This is a cautious, but necessary, path."

That evening, we stood outside of a glass-walled room while our son underwent a barium drop x-ray of his gastrointestinal tract. Suddenly, the radiologist screamed. She picked up the phone and called the surgeon. "You have to see this! His intestines are wrapped north of his stomach! They're about to twist off!" The surgeon arrived and operated on our son, unfurling his intestines, removing twenty-one adhesions, and carefully placing his bowels back in.

Weeks later, after we brought our son home, his recovery was tenuous. Some days, we ended up back at the hospital. Our surgeon called for nightly reports on bowel sounds. Once, we met our pediatrician at her office at eleven o'clock at night; another time, she examined our son's abdomen on a bench at her son's athletic game to ensure that his postoperative discomfort was nonsurgical. Each time we saw each other during that year—and often in the two decades since—we hugged, blinking back tears. As my son began to live a normal boy's



life, we sighed relief. He was, we agreed, "the one who almost got away."

Winning, Or Losing, The Doctor Lottery

Today, my son is six foot two and a senior in college. When he was a newborn, his three-inch scar extended across his belly. Today that scar appears deceptively small. In the decades since, his case has been taught in medical schools and used in lawsuits by parents whose pediatricians hadn't listened and whose children had needlessly died.

Why were we so fortunate? I didn't know it two decades ago, but despite the terror of those weeks in which we almost lost our child, something good, and rare, had happened. We had won what I've since come to call "The Doctor Lottery."

When you win The Doctor Lottery, there is no cash prize but a far greater payoff: the possibility of extraordinary healing, even a miracle. Our son survived because our physician took the time to listen, show compassion, earn trust, partner with us, advocate, and provide just the right amount of care to save a life. She fostered a safe and healing patient-doctor relationship, while navigating us through a sea of uncertainty.

My family and I haven't always won The Doctor Lottery. My father's surgeon, for instance, had pushed him to have the bowel resection to "cure" him of diverticulitis, a disease in which the colon's lining becomes inflamed. He stitched up my father's intestines with a suture known to dissolve in patients

who've been on steroids and hadn't read my father's chart to see that his internist had recently had him on cortisone. Nor did he look at the list of medications my father had carefully written down on his patient intake forms. When the sutures dissolved, my father, who had a bleeding disorder, went into shock. His abdomen was distended and hard.

My mother asked the nurse to page the surgeon. "My husband is in so much pain!" she said. The surgeon, who was playing golf, told the nurse to tell my mother, "Pain after surgery is normal." By the time my father developed a fever, and peritonitis, it was too late. He died of a heart attack. "Normal courses of antibiotics proved unsuccessful," my father's death report reads.

Not only did we not win The Doctor Lottery that day, but my brothers and I lost our childhood. When my father passed away, the world as we knew it ended, as if someone had erased all the color from the horizon.

My Turn In The Lottery

These experiences informed my own health journey when, in 2001, I became a revolving-door hospital patient facing two long periods of paralysis from Guillain-Barré syndrome, a neurological autoimmune disease similar to multiple sclerosis. The day my Hopkins neurologist delivered the diagnosis, I passed through a portal into a terrifying and unknown universe.

As my husband filled out admission papers, my neurologist sat beside my wheelchair, quietly explaining the treatment I would undergo. He would start infusions of other people's healthy immune cells to try to reverse my paralysis. After he finished talking, we sat together in silence. Nurses rapped at the door. His patient waiting room filled. But he never left my side. I asked him why he stayed with me when he had so much to do—he was, after all, the head of a major department. He told me, his eyes looking into mine, "I will not leave you sitting here alone, not with the news I've just given you."

Over the next few months, I slowly learned to walk again. But, although Guillain-Barré syndrome rarely strikes the same patient twice, four years later I developed it again. This time, I fell into

a state of paralysis faster, and the damage to my nerves was more extensive. During my hospitalization, several of my doctor's fellow neurologists warned me to "hope for the best but prepare for the worst." They said that I might never get out of a wheelchair. But my neurologist shook his head and reassured me that some people did recover. He thought I could, too. "Don't listen to them," he told me. "I'm your doctor, I know you."

His words stayed with me during that hot slog of summer into fall, as I sweated in rehab, then through grueling physical therapy at home that left me shuddering and depleted.

Eventually, six months later, I was able to navigate steps with a cane, then walk out my front door and down the driveway.

Finding A Physician-Partner

Some months later, however, like many Guillain-Barré syndrome patients, I still navigated through a flu-like fatigue. I'd also developed symptoms of gastroparesis, a condition in which the stomach can't empty itself normally. A new, local doctor I saw seemed to think me a hysteric and handed me Prilosec. I will never forget the look of disdain on his face the second time I saw him, and he said, "A few days ago you came in saying you were nauseated, and today you say you have diarrhea! Make up your mind!"

I sought out a number of physicians, seeking answers, until in 2011 I met a new internist, Anastasia Rowland-Seymour, at Johns Hopkins, who changed my life by partnering with me to create a new health story.

Dr. Rowland-Seymour asked me gently about my history, never looking at her computer. I told her that I knew I was lucky to be doing so well, walking, driving. I told her of my bone-deep fatigue, numbness, headaches; that I often found myself so tired I had to lie down on the floor after climbing the stairs. "That's my normal," I said with a shrug. I figured our time was up, but she wanted to have a deeper conversation about my well-being.

"You've been through a great deal in a relatively short period of time." She looked as if she didn't quite buy my breezy rendition. "That has to have tak-

People suffer needlessly, or pursue new possibilities of healing, based largely on whether they have a healing doctor-patient partnership.

en quite a toll on you."

She wondered if I thought that the decades of stress I'd faced might have played a role in the immune dysfunction I now faced. She asked me if my childhood, in particular, had been stressful.

I was astonished.

"I've never thought about it that way," I said, telling her, in briefest terms, about my father's sudden death.

That day, I found a partner on my path to healing, one who helped me incrementally incorporate mind-body approaches to well-being with conventional medical care. Over the next year, my health dramatically improved.

After having seen the best and worst of medicine over three generations, I've learned that people suffer needlessly, or pursue new possibilities of healing, based largely on whether they have a healing doctor-patient partnership.

I've seen this pattern in my work as a science journalist, too. I've heard from thousands of patients about relationships with doctors that helped—or hindered—their health and recovery. It's clear that the tenor and quality of the patient-doctor relationship play a telling role.

Every patient wants and deserves to win The Doctor Lottery; it shouldn't be simply a matter of chance. The good news is that I believe we can get there, in three key ways.

Feeling Known

In my healing encounters with physicians, I felt that I was being heard, understood, and respected. My internist, Dr. Rowland-Seymour, now at the Case Western Reserve School of Medicine, trains medical students in gaining skills to create a sense of safety and partnership with their patients. Through simulated role-playing exercises, she shows

students how to create trust from the moment they meet a patient, such as by letting the patient walk in the room and sit down first and asking open-ended questions such as, "What else is coming up for you?"

A 2015 study in *Narrative Inquiry in Bioethics* found that patients overwhelmingly felt that what mattered most was having a physician who listened, acknowledged their condition, was honest, and treated them as an equal. A 2006 study in the *Journal of General Internal Medicine* found that the single greatest predictor of whether patients with HIV adhered to treatment was whether they felt "known as a person" by their physician.

The first time I met Dr. Rowland-Seymour, I entered the exam room ready to focus on managing symptoms. I was surprised to discover that past trauma might also need to be addressed if I hoped to improve.

When physicians don't take the time to listen and be present, their patients are less likely to trust their decisions. In a 2015 study in *JAMA Oncology*, patients with poor relationships with their physicians were more likely to demand added tests and procedures.

"We know that when people feel they have been fully heard and seen in a relationship, they are more likely to heal," says Bob Whitaker, a professor of public health and pediatrics at Temple University. That's helpful to a patient even before doctors intervene with traditional medicine, he adds.

When I think of the extraordinary doctors in my family's healing stories, they shared something in common. They were deeply present during our encounters, as if they were there to stand shoulder to shoulder with us—rather than simply to give directives. Because they established that rapport, they helped us navigate uncertainty in the face of terror, while still championing real hope for recovery.

This doesn't mean offering a patient false hope, Dr. Rowland-Seymour underscores, but rather "a sense that we are going to figure out how to manage this, and get you better, and we are going to do it as a team."

Understanding Past Trauma

Most physicians are trained to “walk around trauma as the elephant in the room,” Dr. Rowland-Seymour says. If they don’t see a direct correlation between how trauma has affected a patient’s well-being and long-term health, they sidestep it. But you can’t achieve true healing with that elephant in the room.

Jeffrey Brenner, a 2013 MacArthur “Genius” Fellow and senior vice president of integrated health and human services at United Healthcare, where he leads myConnections, a program to pilot new models of health care, is an advocate for training medical students to screen patients for trauma. He has found in his own clinic that knowing about patients’ early-life trauma “is as important as knowing their vital signs.”

When physicians grasp that past trauma can affect current physical health, they can also better understand why poor health habits might be coping mechanisms for past wounds, and why it is especially difficult for some patients to engage in the kind of self-care that’s critical to healing.

Trauma awareness also helps physicians recognize their own past trauma and stress. According to Henry Weil of the Columbia University College of Physicians and Surgeons, the physician who has developed self-awareness of his or her own suffering, and the effect that trauma has had on his or her life, is often best able to view patient suffering “with an open heart.”

Misaligned Incentives

Yet even when new doctors are trained to foster a strong patient-doctor relationship and recognize trauma, the system all too often pushes them in the opposite direction. After medical school, physicians quickly learn that they’re better rewarded for moving fast than for taking a thorough patient history. In a hospital clinic setting, internists have fifteen minutes to see each patient, which might be fine if the patient has a sore throat, but in large teaching hospitals, most patients are struggling with multiple, complex chronic conditions.

The physicians with whom I’ve spoken agree that doctors who put in the extra time to create relationships with pa-

My father’s unnecessary death inspired me to insist on having doctors who listened and treated me with respect.

tients do it because they feel it is the right thing to do, despite the fact that the system doesn’t reward their efforts. But a system that relies on physician good-heartedness alone is hardly sustainable, especially given that half of physicians already report professional burnout.

The good news is that a quiet revolution is now afoot in medicine. Many doctors, just like their patients, long to have more healing encounters and foster strong patient-doctor relationships. To achieve that, we will have to rethink how we deliver medicine.

How To Shift The Paradigm

Ensuring that more doctors know how to foster a healing relationship means that medical schools will need to reenvision how they select the right students, and deepen their training. This goes beyond teaching students and interns to maintain eye contact or use open-ended inquiry. It will require teaching mindful, empathic listening and rewarding doctors-in-training for developing strong patient-doctor communication skills and relationships. Compassion and empathy training—tailored to the physician experience—are particularly important during the grueling years of medical training, but all doctors should revisit these skills as part of continued medical education.

We also need to revisit how time during the face-to-face patient encounter is being used.

“Good things have come from technology, but technology can’t do everything we thought it could,” Dr. Whitaker, of Temple University, says. “If a physician has their back to the patient, and is looking at the computer while taking a patient history, that’s not a healing encounter.”

As Dr. Rowland-Seymour pointed out to me, dentists often have a scribe taking notes while they do a dental exam, but

internists don’t. Trying to connect with patients while staring at a computer screen just doesn’t make sense. Vikas Saini, president of the Lown Institute, suggests incentivizing the development of systems that use voice recognition software and artificial intelligence to extract relevant patient data from voice or video recordings, thus freeing the physician to be more present with patients.

Primary care physicians and other providers are already helping drive the types of changes that make it more likely patients will win The Doctor Lottery. For one, they are moving toward value-based care delivery and payment models, which reward meeting quality-of-care targets as opposed to simply paying for the quantity of care. Team-based care, in which a doctor works as a member of a larger team (including, for instance, a medical assistant, social worker, and behavioral health expert), also can create a more healing environment and ensure that all of a patient’s needs are addressed. Lastly, greater attention is being paid to transitions in care, to ensure that care runs smoothly across various settings, especially when multiple providers are involved, so that life-saving information is never lost in translation. All of these strategies rely upon doctors listening to, seeing, and respecting their patients—and on measuring care not only by their actions but by their presence.

But real change won’t happen unless physicians place value on these qualities within themselves and within the profession.

I only wish it weren’t too late for my father to have won The Doctor Lottery. His unnecessary death inspired me to insist on having doctors who listened and treated me with respect. It is bitter-sweet that my dad’s unintentional legacy was the very gift that would help me reclaim my health and save the life of the grandson who, sadly, he never got to meet. ■

Donna Jackson Nakazawa

(donnajacksonnakazawabooks@gmail.com) is an award-winning science journalist and the author of *Childhood Disrupted*, *The Last Best Cure*, and *The Autoimmune Epidemic*. She lives in Baltimore, Maryland, and is currently at work on her sixth book.