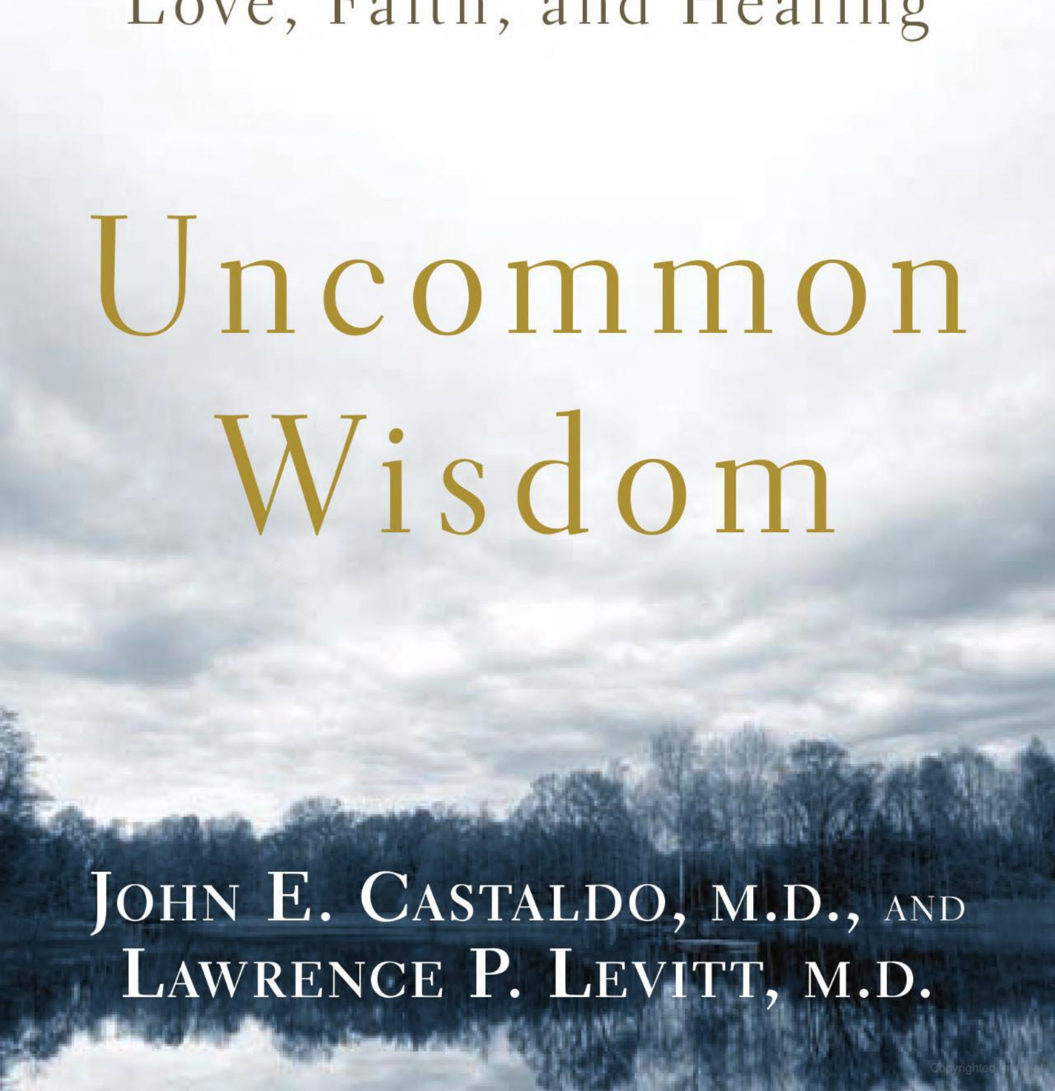
True Tales of
What Our Lives as Doctors
Have Taught Us about
Love, Faith, and Healing



Uncommon Wisdom

John E. Castaldo, M.D., and
Lawrence P. Levitt, M.D.

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CONTENTS

ENRICHING CONNECTIONS

HUMBLE LISTENING

GOING THE DISTANCE

SORROWS' LESSONS

LOVE HEALS

LEAPS OF FAITH

AUTHORS' NOTE

We were gratified by the positive reaction to our book *The Man With the Iron Tattoo,* first published by BenBella Books of Dallas, Texas, in 2006. We will always appreciate the efforts of Glenn Yeffeth, CEO, and his colleagues.

For Rodale's edition, we added three chapters that follow the book's theme of life lessons we learned from our patients. We also changed the title to *Uncommon Wisdom: True Tales of What Our Lives as Doctors Have Taught Us about Love, Faith, and Healing,* which we think more accurately reflects what the book is about. We hope our readers enjoy the results.

—J.E.C. and L.P.L.

INTRODUCTION

THIS BOOK IS ABOUT science and spirit; it is about the splendor of the human brain and the grace and courage of human beings in the face of daunting challenges. It is also about the ways in which people transform each other, often without ever knowing it.

We are neurologists—"brain doctors"—who have been partners in a busy academic and clinical practice for twenty years. For many of those years, we chose to share a consultation office, which was furnished with one brown oak desk and two chairs. As our partnership and friendship deepened, we learned much from each other. Some of what we learned was about neurology—about multiple sclerosis, Parkinson's disease, stroke, epilepsy, and other conditions that affect the brain, spinal cord, peripheral nerves, and muscles. These are diseases that can suddenly and dramatically shift a life: one day a patient is relatively normal; the next, he or she is unable to pick up a spoon, walk, speak, see. It is a world of harrowing difficulty and, sometimes, unexpected opportunity.

As we learned more about these neurological conditions and how to treat them, we began to realize that we were also gaining wisdom from our patients—wisdom about how to live. We were also learning much from family members who often confronted wrenching change in a loved one, and therefore in their own daily roles and rhythms. We feel fortunate that relatively early in our lives, our patients and their families were willing to teach us lessons that we ourselves needed to learn.

And so, after writing numerous articles and book chapters for physicians, physicians-in-training, and medical students, we began to write of encounters with some of our patients, in plain language and, we hope, with honesty and directness. All of the cases presented here are true; some names and details have been changed to protect patient and family privacy.

While the stories that follow encompass a number of intriguing medical challenges, more essentially, they trace emotional and spiritual upheaval, turning points, and growth. We share with you, the reader, the fears, longings, sorrows, and satisfactions of being doctors, and the ways we have been profoundly changed by the people we have treated. Looking back, we realize that the "uncommon wisdom" that our patients have shared with us is founded on the values that our parents once tried to teach us, but perhaps at a time when we were not ready to truly listen. This wisdom, grounded in love, faith, forgiveness, and healing, is at the core of the book.

We hope that the stories you're about to read prove not merely interesting, but useful to you. For the book addresses an essential human question that extends far beyond matters of the brain: In the face of any enduring challenge, how do we live with joy and hope? It is a question we continue to ponder and learn about from our patients, colleagues, families, and friends. We invite you to join the conversation.

—J. E.C. and L. P. L.

ENRICHING CONNECTIONS

ENCOUNTERING LEONARD

"MRS. POOL?" I SPOKE softly to the frail, gray-haired woman lying motionless on the bed. There was no response. "Mrs. Pool?" I ventured again. "Can you tell me how you're feeling?"

The sheets stirred slightly. "Very weak," she finally whispered. She reached out to touch my hand, mumbled something unintelligible, and drifted off to sleep again, ending my interview before it really got started.

I was a first-year resident at Memorial Sloan-Kettering Cancer Center in New York City, and feeling frankly overwhelmed. I knew that Dorothy Pool had been recently diagnosed with lung cancer and had traveled to our hospital from her home in Allentown, Pennsylvania, after becoming suddenly and unaccountably weaker. Her doctors in Allentown couldn't figure out the source of her precipitous decline, which is why her husband, Leonard, had been advised to bring her to Sloan-Kettering. We were their last hope. Mr. Pool was sitting on a chair across from his wife's bed, looking up at me with a mixture of sadness and stoicism. I could imagine him thinking: "Too young, too inexperienced. Wasting our time."

If Mr. Pool was thinking that, I said to myself, he was probably right. I was twenty-seven years old and green to the gills, stuffed with textbook knowledge but not much experience with actual patients, much less their families. My first impulse was to flee the room, just to get away from the sadness in his eyes. "Dr. Levitt?" I heard him say. "Could we talk a moment?"

Apprehensively, I sat down in the green vinyl chair opposite him. I expected him to start peppering me with questions. *Exactly what do you plan to do to get to the bottom of my wife's sudden deterioration? What treatments will you try? What are her chances?* But Leonard Pool just looked at me and smiled. "It's good of you to help us," he said simply. A lean, fit man with alert hazel eyes, he appeared to be in his early sixties, several years younger than his wife. He was dressed in corduroys and a plaid flannel shirt, and had the look of someone who'd worked outdoors his whole life.

"We will certainly try," I said, with more confidence than I felt. "Perhaps you could tell me a bit more about your wife's condition." Nodding, he told me that Dorothy had been diagnosed with lung cancer earlier that year, after three decades of chain smoking. "I tried to get her to stop, but . . . " He trailed off, shaking his head. But after she'd undergone a round of radiation, he continued, she'd recovered some of her energy. She'd been going out with friends, taking walks in the countryside, even traveling to visit her sister in Detroit. Then, two weeks ago, she became suddenly and overpoweringly exhausted, "as if all the energy had been just scooped out of her," Mr. Pool said. "She got so weak she could barely stand."

As he said this, he let out a deep sigh and stared out the window into the hospital parking lot. His hands, ropy with veins, gripped the sides of the chair. Somehow, I got the distinct sense that he was picturing his wife's death.

For the second time in ten minutes, I wanted to run out of the room. It all felt like too much responsibility, not just to diagnose and treat this woman's strange symptoms but to know that so much feeling—a lifetime of love and protectiveness, I guessed—hung in the balance. What if we couldn't help her? "Well," I said awkwardly, "try not to worry." *Brilliant, Levitt*, I thought. *Why shouldn't this man worry?* "We'll do our best to help Mrs. Pool," I added lamely. I couldn't take this anymore. I got up from my chair, made some feeble excuse, and escaped out into the hall.

Over the next two days, I worked with my attending physician, Dr. William Geller, to try to figure out the cause of Dorothy Pool's mysterious weakness. We ordered up blood tests, a routine step following a hospital admission, but one that often elicits nothing worthwhile. But as we analyzed the results of Mrs. Pool's sample, our first clue emerged: a key blood salt known as serum sodium had fallen to a critically low value. The salt had plunged low enough to cause excess fluid to flood delicate brain tissues, which would produce exactly the kind of progressive weakness and lethargy that Dorothy Pool was experiencing. Dr. Geller and I both knew that if the cause of this plummeting blood salt was not promptly uncovered and treated, Mrs. Pool would quickly die.

Dr. Geller immediately dispatched me to research Mrs. Pool's cancer type, known as small cell carcinoma. This was 1967, long before the Internet would make medical research a matter of a few mouse clicks. Back then, we went down three floors to the hospital medical library, where we first looked up our subject in a series of ten-pound reference tomes known as *Index Medicus*. This process, in turn, directed us to specific issues of medical journals that featured articles on the subject we were hunting down. Then we combed the cavernous library stacks until we found those journals. Finally, we sat down to read the relevant articles therein.

As I hunkered down into a library carrel with a stack of journals piled high in front of me, I again thought of Mr. Pool's face as he stared out onto the parking lot—his mixture of sadness, forbearance, and undisguised pain. I realized how much I wanted to make a difference to his wife—and to him. Still, given her clearly critical condition, what were the chances? As I was thinking this, I was paging through a study on small cell carcinoma in a little-known medical journal. Suddenly, I sat up straight. The small cell tumor, I read, was distinctive in its ability to secrete a potentially deadly substance called antidiuretic hormone. I knew that in healthy people, this hormone was secreted in very small amounts by the pituitary gland. But in some cancer patients, the article went on, this hormone can be released in toxic quantities by the tumor itself and wreak havoc on the body's ability to regulate salt and water.

My heart racing, I read on. The most effective treatment for the disorder, called Syndrome of Inappropriate Antidiuretic Hormone (SIADH), was to restrict water intake, because it caused the sodium to rise back to normal levels. Quickly, I photocopied the study and ran back upstairs to intercept Dr. Geller. He scanned the article, quickly nodding his head several times as he read. Then he looked up at me, smiling.

"Let's get started."

Together, we went to Dorothy Pool's room to explain our recommended treatment to her husband. We explained that while "water restriction" might sound a bit draconian, in fact we were advising that Mrs. Pool limit herself to the equivalent of three glasses of water a day—less than half the amount most people ingested but more than enough to prevent thirst. As we stood at her bedside outlining our plan, I watched Mr. Pool's face brighten with hope. "We think this is a very promising approach," Dr. Geller told him. "But of course, we can't guarantee that it will reverse Mrs. Pool's symptoms." At his words, I found myself filled with anxiety. It *had* to work!

Later that evening, shortly after starting Mrs. Pool's treatment, I entered her hospital room feeling bad that I had left too soon earlier that day, and found her husband sleeping on a cot next to her bed. I'd noticed the cot there before and realized, with a start, that Mr. Pool probably couldn't afford a hotel room. Though he'd never mentioned what he did for a living, he'd told me that the Allentown, Pennsylvania, area was a farming and industrial community, so I gathered he was a laborer of some sort. The next morning, over breakfast, I told my wife, Eva, what I'd seen. "You must invite him to dinner!" she said. "He probably hasn't had a decent meal or sat in a comfortable chair in a week." I nodded, ashamed that I hadn't thought of this myself. "Bring him here tonight," Eva said firmly.

And so that evening, I brought Leonard Pool back to our small apartment on Fourteenth Street near First Avenue, in the Union Square neighborhood of New York City. As we walked through the door to the aroma of roast chicken, Mr. Pool seemed to almost palpably relax. "Well now," he said, after I'd made introductions, "this is just what the doctor ordered!" Then he asked that we call him Leonard. As he grinned broadly at the two of us, I saw that Eva had been right. His wife might have been the patient, but this man badly needed a little TLC.

I can't remember everything we talked about that evening, but I'm sure that we discussed Dorothy, who already seemed to be responding, ever so slowly, to treatment—her blood pressure had risen slightly and she was now able to speak a few sentences at a time. Leonard talked about what an amazing woman she was, an accomplished pianist and painter who lived every day to the hilt and had "the best laugh in the world." I could tell that Leonard was still very worried about her, and I wanted to reassure him, to say something heartening like "I'm sure she'll be fine," but I managed to swallow it. I wasn't at all sure she'd be fine. I knew I had no right to give Leonard, or anyone, false hope.

As we sat around our Formica-topped kitchen table eating Eva's delicious chicken and roasted carrots, Leonard also asked me a number of questions about my work and our future plans. What kind of doctoring most interested me? In what area of the country would we most like to settle? He seemed genuinely interested in both of us. When I asked him what he did, he just murmured "this and that" and asked us what it was like to live in Manhattan. At the end of the evening, he said he hoped that when his wife had recovered her energy, we'd come and visit them in "our wonderful city of Allentown." When Eva responded, "Alan who?" we all laughed, and she admitted that she'd never heard of Leonard's hometown. I didn't add that I'd never heard of it, either.

When I returned to the hospital the next morning, I checked in on Dorothy Pool to find her sitting up in bed, eating breakfast. Leonard, sitting next to her, was positively beaming at me. "Would you look at *this*?" he said, proud as a father showing off his child's first steps. By the following day, Dorothy was up and moving about the room, chatting with visitors. "It's a miracle!" Leonard said exuberantly, and though I didn't say so out loud, I thoroughly agreed with him.

When I'd first seen this woman, gray-faced and still, she looked as close to death as a person could be. Now she was walking around, cracking jokes and laughing—she *did* have a wonderfully infectious laugh—and planning all of the things she and Leonard would do when they returned home. When she was discharged a few days later, both of them hugged me. I found myself saying: "I'll miss you both."

And I reflected on the awesome power of medicine to make a difference—even when, at first glance, things look hopeless. Mrs. Pool was the kind of patient that doctors tend to easily give up on. She was elderly and already had advanced cancer. But I learned from her that if you can figure a case out early enough and if a particular symptom is treatable, you can improve the quality of someone's life even if he or she has a serious, fatal illness. It's vital to focus on what *can* change—an infection that can be quashed with antibiotics, an out-of-whack electrolyte balance that can be restored with IV fluids, a nutritional deficiency that can be reversed with a dietary adjustment. Small victories. From that day, I followed an unspoken motto: "Treat the treatable."

A few weeks later, I was on rounds when the hospital's loudspeaker suddenly crackled to life. "Dr. Lawrence Levitt," a disembodied voice intoned, "please report to Mr. Van der Walker's office immediately." My heart froze. Mr. Van der Walker was the president of Memorial Hospital. Being summoned to the head office was, by definition, bad news: It nearly always meant that a resident had done something terribly wrong, either medically or ethically. In the few cases I knew of, this kind of summons had been followed by suspension, or even discharge from the program. Once booted from an institution as outstanding as Sloan-Kettering, what other residency program would touch me? I saw myself giving up my dream of doctoring to join my father's fur business, where I would live out my days peddling fox stoles to rich matrons. I felt physically ill.

As I buzzed the elevator to take me to the top floor, I racked my brain for what I might have done wrong. I was pretty sure I hadn't made any major medical errors; if I had, my attending physician, Dr. Geller, would have already called me on the carpet. But I knew that fraternizing with patients' families was considered, if not unethical, at least highly unprofessional. Had someone seen me leaving the hospital with Leonard? Had somebody on the staff reported that I'd hugged a patient? I'd already been told by my superiors that at times I was "inappropriately expressive." Had I crossed some final, forbidden line that I hadn't even known was there?

As I entered the corner office of Mr. Van der Walker, I saw a blur of Persian rugs, heavy furniture, and great swags of silk drapery. Behind a massive mahogany desk sat Mr. Van der Walker himself. He was a tall, wiry man, impeccably dressed in a navy three-piece suit, red tie, and crisp white shirt. His pale blue eyes were cold.

"Are you Dr. Levitt?" he demanded.

"Yes, sir," I mumbled, trying hard to not drop my eyes.

"Do you remember the Pool case?" To my ears, the question sounded like a bark.

"Of course," I responded, my heart sinking. *Here it comes.*

"Well, your patient's husband, Leonard Pool, just came to see me," Mr. Van der Walker said. Confused, I watched the corners of the CEO's mouth turn up, ever so slightly. "He wanted to express his appreciation to you and Dr. Geller for the kindness and care you extended to him and his wife."

I closed my eyes, almost dizzy with gratitude and relief.

"Thank you for letting me know, sir," I managed to reply.

But Mr. Van der Walker wasn't finished. "You may not be aware," he said, "that Leonard Pool is the founder of a major chemical company, Air Products and Chemicals, in Allentown, Pennsylvania."

"Mr. *Pool*?" I said incredulously. I flashed on his plaid work shirts, the hospital cot.

"Yes, a highly successful gas and chemical company," Mr. Van der Walker continued. "And in appreciation of your care, he's just pledged one million dollars to Sloan-Kettering."

I just stared at him, my mouth sagging open.

"So I, in turn, would like to express my thanks to you," said Mr. Van der Walker, sliding his long body out from behind his desk to shake my hand. I didn't hear much of anything else Mr. Van der Walker said, but he probably tried to end the interview several times because at some point he simply took my elbow and ushered me toward the door.

Leonard never mentioned his gift to me. But he did stay in touch, letting me know that after returning home, Dorothy had been able to dine out with friends, paint watercolors, and even play bridge. Then, after a few months, she relapsed again and was brought back to Memorial. By this time, her cancer had advanced to the point that no treatment could help her. As before, Leonard stationed himself next to her in the hospital room, on a chair by day and a cot by night. She died in the hospital, with her husband by her side.

Leonard continued to stay in touch, visiting Eva and me often on his business trips to New York City. But he wasn't through surprising me. A few years later, he orchestrated a recruitment effort to persuade me to join Allentown's Lehigh Valley Hospital as its first full-time neurologist. After several visits there, Eva and I both understood why Leonard and Dorothy loved this lushly green, community-spirited town. Though my Bronx-born self protested—*what, are you nuts?*—I astonished myself by accepting the offer. During his lifetime, Leonard donated $5 million to launch the fund drive to build Lehigh Valley Hospital. When he died three years after we moved to Allentown, he left his $17 million estate to the Dorothy Rider Pool Health Care Trust, which he'd created expressly to encourage Lehigh Valley Hospital to grow into a major teaching and research institution. He wanted Allentown to have the kind of hospital that would allow seriously ill people to get first-class medical care right in their own community, especially people without the Pools' financial resources. My participation as a trustee on this charitable foundation—for three decades now—is one of the most satisfying experiences of my life.

•

A large portrait of Leonard Pool hangs in the front lobby of our hospital. When I look up at it, I often ask him silently: "How am I doing?" Sometimes I have the feeling that he's pleased. He'd be happy; I know that the citizens of Allentown and surrounding communities now have access to a fine academic hospital with the state's first hospice, a cutting-edge trauma center, a burn center, and a cardiovascular disease prevention program that has become a national model.

But at other times, I think Leonard expects me to do more. Not more in the way of fund-raising or hospital-building. Instead, I get the feeling he wants me to remember to pay the right kind of attention to patients and their families, and make sure that other doctors do, too. It's as though he knows how busy I've gotten, how distracted I can be as I rush from appointment to appointment, meeting to meeting. He wants to make sure, I believe, that we doctors stop to look around and notice the people in the hospital who seem anxious, frightened, or lonely. He wants us to sit down, take the time to hear what matters to them. And, if the moment seems right, well, the heck with hospital protocol. Invite them home to dinner.

HELLO, GOOD-BYE

WHEN YOU ENTER A hospital emergency department, commonly referred to as the "ER," the first thing you notice is the noise. A dozen IV pumps beep for attention, patients moan in pain, babies cry, physicians issue orders to nurses for medication, and nurses shout to other nurses for additional help while the overhead telecom repeatedly blares its urgent demands. It is a dissonant orchestra playing to a captive, discontented audience. Almost no one wants to be there.

As I hurry through the doors of the ER in response to a page, no one looks up from their harried tasks. There are no waves, no nods of greeting. I am a ghost floating through the chaos, searching for a clue that someone needs a neurologist.

"Oh, John," a voice calls out. It's Dick Blaney, one of the emergency room physicians. "I paged you because there's a woman in room six that I just can't figure out. She's been here all day, actually. She's got an awful pain behind her eye that makes no sense to me. Mind taking a look at her?"

"Room six. I'm on it, Dick, thanks," I said, getting my bearings.

Momentarily, I wondered why he'd taken all day to call me, leaving a patient in severe, unexplained pain. But then again, this was the ER. The tragically near-dead received attention first. If you were in severe pain, but more dangerously ill patients kept coming through the door, you often slid to the bottom of the queue over and over again before a doctor had the time to evaluate you thoroughly. It was the reason that some patients simply walked out of the ER, frustrated and furious, without ever being seen by a physician.

Room six was two steps away from me, in the area of the emergency department where the less intensely sick marked time, like planes circling an airport but not permitted to land. Picking up the medical chart hanging outside the door, I knocked on the door frame of the cubicle, and then gently pulled back the privacy curtain.

A woman in her mid-forties lay on a gurney in her street clothes, holding a hand over her face.

"Hi," I said, trying to muster an engaging smile. "I'm your neurologist du jour."

"Hi, Dr. Castaldo," she said, smiling back with effort. "We've never met, but I know you. I'm your neighbor living a few houses up on Celia Drive. Our children go to school together on the same bus." I looked up from the chart and met her eyes. I didn't recognize her. "I see your three boys on the block all the time," she prompted. "They're great kids."

I suddenly felt foolish and ashamed that I didn't know my own neighbor, someone who knew me well enough to call me by name. I quickly scanned the chart bearing her name and address on Celia Drive. She lived only ten doors up the road, but I didn't even recognize her name: Louise R. Marinelli; date of birth, 07/23/54. That was my birthday! We were exactly the same age, born on the same day, month, and year. But I hadn't even known she existed.

As our eyes met again, a great sadness came over me. I felt the pain of disconnectedness from my own community. My work as a doctor had become all-consuming, transforming me from someone who had once loved to socialize, exercise, and volunteer in my community to a white-coated, cloistered monk. Training to be a neurologist had taken nearly twelve years of my life. After that, I'd somehow imagined that being a doctor would be easy to balance with the pleasures of family, friendship, and creative pursuits.

But I hadn't counted on the demands—and the seductions—of doctoring. It seemed that there was always another patient who needed more attention, a bit of lab work that needed more study, a new neurology journal to be read, a case that needed further deciphering, or a family (other than my own) that needed consoling. Then I'd become involved in academic research, sapping the little remaining free time I'd carved out. In that moment, I saw my life clearly: I'd become consumed by the voracious beast of medicine, along with its sidekick, my own perfectionist personality.

Just try and leave me! the beast roared in my head. *Without me, you're nothing!*

What was left of me? And could I get back what I'd lost?

"Dr. Castaldo? Are you all right?"

I snapped back to the present. "Uh, pleasure to see you, Mrs. Marinelli," I stammered, managing a smile that I hoped hid my confusion and distress.

"Please call me Louise," she responded, trying to smile back.

As I moved closer to introduce myself, she shook my right hand with her upside down left one. It was then that I noticed that her right arm was paralyzed and atrophied, held close to her body in a gray silk sling.

Having rushed to the ER that morning from her job, Louise was still dressed up in a three-piece charcoal pin-striped suit and crisp white blouse. Her hair, naturally blond, was elegantly styled short and tucked in below the jawline, accenting her high cheekbones. She wore ruby-red lipstick and her fingernails, manicured to perfection, were lacquered to match. It was painful to witness the contrast between this woman's flawlessly groomed appearance and her inner suffering. Tears streamed down from her left eye, streaking her makeup and staining her outfit.

"I'm in *so* much pain," she whispered, cupping a delicate hand over her left eye. "I don't mean to be a baby, but I can't take this any longer." She told me that she'd seen my partner, Bill Robertson, earlier that day and that he'd ordered some tests and given her some medication, which had barely touched her pain. "Finally," she said, "it got so bad that I came to the ER."

I looked at her prescription medication for Darvocet N 100, a fairly powerful pain pill. Only a few things in the field of medicine could produce a degree of pain so acute that a narcotic like this couldn't relieve it. But I didn't want to jump to any conclusions until I'd heard more from Louise.

"Tell me more about what you're experiencing," I asked gently.

She told me that the pain had started "as a little nothing" a week earlier, but had escalated in frequency and severity each day afterward. "Can you tell me what it feels like?" I asked.

"Well . . ." She paused, wincing as she withstood another jolt. "It feels like a huge electric shock to the back of my right eye," she said, shielding her eye with her hand to protect it from the glare of the fluorescent lights.

"Is the pain constant, or does it come on in quick lightning bursts?" I probed, searching for cues.

She looked up at me, wan and weary from pain, sleeplessness and, no doubt, my relentless questioning. Then she flinched five or six times in quick succession, as though she'd been fired at by a machine gun. As she waited patiently for the attack to subside, tears streamed from her afflicted eye. My heart ached for her.

"It comes in brief lightning bursts," she finally said. "Just when I think it's over, it starts up again." She looked at me beseechingly. "Help me, please."

I hated to keep asking her questions, but I knew that it was crucial to learn as much as possible about her condition and history so that I could treat her effectively.

"Louise, have you ever had any other medical problems?" I asked.

"Oh no, I'm healthy as a horse, normally," she said. "It's really unusual for me to even see a doctor." There was a silence as she saw me gazing quizzically at her paralyzed arm.

"Oh, right, my arm," she said matter-of-factly, as though it were a minor inconvenience. "That's what I've been seeing Dr.

Robertson about. He's done a bunch of tests but nobody is quite sure what's going on with it. I guess the latest theory is that it's a late effect of radiation."

"Radiation?" I asked. This was an unexpected twist.

"Oh, right, I guess I forgot to tell you about my breast cancer."

I looked at her intently. "Do you have breast cancer?"

"*Had,*" she corrected, again cupping her hand over her tearing eye. She went on to tell me that she'd been diagnosed with breast cancer twelve years earlier, at the age of thirty-two. She'd pulled through a mastectomy, radiation, and chemo, and at her malignancy-free checkup ten years later, her oncologist had told her that the cancer was unlikely to ever return.

But the last year had not gone so well for Louise. She'd developed a chronic, low-grade pain in her right shoulder, limiting her range of motion and gradually weakening her arm and hand so much that she'd had to learn to function entirely with the left. An MRI (magnetic resonance imaging), EMG (electromyogram), CT (computed tomography), and second and third opinions from specialists had reassured her that the problem was not recurrent cancer. "At least I've kissed *that* problem good-bye," she said, her voice a mix of relief and quiet triumph.

I believed that Louise was right. After twelve years and no recurrences, it was highly unlikely that breast cancer had anything to do with her current problem. More likely, she was suffering from very late effects of radiation therapy on her breast and chest, which now was showing up in progressive weakness of her dominant hand and arm. The arm weakness was probably caused by radiation-induced injury to the brachial plexus, a cluster of nerves that exit the neck, become entwined just below the collarbone, and then are dispersed to provide motor movement and sensation to the arm and hand.

I looked more closely now at Louise's paralyzed limb. The muscles of the arm were atrophied and jellylike. Her hand was curled shut, fingers tight to the palm and completely useless except as ballast to her good left side.

"This past year must have been just terrible for you," I said. "How have you coped with the progressive paralysis of your dominant arm?"

Her pain seemed to settle down for the moment. "Oh, I'm a quick study," she said lightly. "You should *see* what I can do with my left arm." Deftly slipping a pad of paper and a pen from her black carry purse, she quickly wrote a sentence with her good left hand and offered it to me to read.

The sentence, written in perfectly legible script, inquired: "You'd have given your right arm to save your life, too, wouldn't you have?" When I looked at her, her head was impishly cocked, as though waiting for my answer.

I thought about it. I tried to envision myself with my right arm bound helplessly in a sling, trying to get dressed in the morning, and then attempting to make rounds, examine patients, eat, write, and drive, all without the help of my good arm and hand. Even with my strong religious faith and the support of family and friends, I couldn't imagine handling such a disability with anything like the equanimity that Louise was displaying. I wondered how she could suffer so much loss, and now so much pain, and still maintain the warmth and lightness of spirit that seemed to shine from her.

All I knew was that I wanted deeply to help Louise. She was my patient, of course, but it was more than that. Maybe because we were born on the same day, or maybe because she was my neighbor, I felt strangely connected to her. Maybe it was because she had awakened in me the sadness of my alienation from my community and a longing to break out of my isolation. Whatever the reasons, I was determined to find out what was causing her so much pain. And I was determined to cure her.

Excusing myself from her cubicle, I sat down in front of one of the ER computers, typing in "Marinelli." I was immediately struck by the amount of missing and inconsistent information in her record. Her mastectomy report noted that the cancer had been completely removed. As for the weakness in her arm, electrical testing was inconclusive for radiation injury to the nerves of her brachial plexus. Both an MRI and CT scan of that area had come back normal.

My partner, Bill, who had been seeing Louise for about a year, had sent her down to Philadelphia to the University of Pennsylvania for a second opinion some six months ago. The specialists there were similarly uncertain about her condition, but by process of elimination had made the diagnosis of radiation nerve injury. Yet a note from her radiation oncologist documented that she had not received sufficient doses of radiation to produce arm weakness. Thus far, every conclusion about Louise's condition seemed fraught with guesswork and contradiction.

Could she mistakenly have received an overdose of radiation? Possibly. But even if she had, why would she be suffering the effects ten years out, rather than two or three years out, when few doses of the Tegretol, so it was too soon to know if it was going to help. But Bill had also ordered an MRI scan of the brain for her, which meant that he was searching for something else. He, too, must have been baffled by the location and pattern of her pain.

After examining Louise, I found no further clues to a diagnosis. But I remained certain that her pain was descriptive of trigeminal nerve pain following the path to the eye. My concern was that there might be a mass pressing on the nerve at the base of the skull. As I considered this, I felt suddenly chilled. I was certain that Bill was thinking the same thing when he ordered the MRI.

But my job now was to reassure my patient. "Louise," I said, "I'm admitting you to the hospital so we can get your pain under control and do some further tests. I think I know where your pain is coming from; I just don't know why yet. But I promise you I'll find out, and tonight if possible."

Louise was curled up in the bed in a fetal position. By now, tears from her right eye had soaked the pillow as well as her suit jacket and blouse. She nodded mutely.

My mind swam with possible conditions that matched Louise's symptoms. The most hopeful scenario was a case of atypical trigeminal neuralgia, which might well be cured by Tegretol alone. Another possibility was that she was suffering from some kind of inflammation, infection, or abscess at the base of her skull. But it could also be cancer. There were many types that could migrate to the base of the brain—breast cancer (though we'd ruled that out), lung cancer, kidney cancer, or lymphoma. My hope was that getting pictures of the brain with a CT scan or an MRI would move us closer to a diagnosis, and then to a cure.

I took another peek at Louise, who was now lying on her side in a more relaxed position and finally seemed to be getting a little rest. I popped open the curtain and looked around the ER. There was a baby crying at the top of its lungs, an elderly woman repetitively calling "Nurse! Nurse! Nurse!" and a young athlete with a fractured arm groaning in pain; all of these human sounds were lost in a tempest of telephone rings, pager beeps, overhead telecom paging of trauma doctors, and static-choked ambulance reports on incoming patient status. Louise was drowning in that clamor and commotion, and no one was taking notice. I needed to get her a life raft immediately.

I stepped out of the room, drew the curtain behind me, and quickly found a nurse. "Emily, I know you're crazy busy, but I have a patient in room six in extreme pain," I said. "She needs a higher dose of Tegretol right now and some morphine IV if we're to get her comfortable tonight." I jotted the orders on Louise's chart.

Emily looked at my scribbles and raised an eyebrow. "That's a pretty hefty dose of morphine," she observed. "Are you sure you want it IV?"

For a moment, I hesitated. I knew that the side effects of too much morphine could be respiratory arrest, critically low blood pressure, and irregular heart rhythms—all potentially life-threatening conditions. But I also knew that Louise's pain was stimulating her adrenal glands to dump tons of epinephrine into her bloodstream, which in turn was kicking her heart and blood pressure into dangerously high gear. I checked her vitals: blood pressure, 180/100; heart rate 130 beats per minute. Both abnormally high. I made the kind of on-the-spot judgment call that doctors regularly must make—in this case, that a patient's pain was likely more hazardous than a powerful narcotic.

"Give her the morphine IV, Emily."

Next, I quickly wrote an order for a CT scan of the head, to try to get more information about the nature of the mass pressing on Louise's nerve. I knew Bill had been right in ordering the MRI, because it was a better test in evaluating the brain and often showed things that CT scanning missed. But the MRI wasn't scheduled until the following day, and I wanted to see something now. I could feel tightness in my chest, driven by my discomfort about having already begun to treat Louise's pain without a clear diagnosis. This was always risky. The good physician always makes a diagnosis first, and treats second. But I'd made a second judgment call: Louise was suffering far too much to follow standard medical protocol.

As we awaited a call from the CT unit, I reviewed what I knew of Louise's condition. Because I'd been schooled in the anatomy and physiology of the brain, I knew that her syndrome involved the trigeminal ganglion, the large collection of nerve fibers that gathers at the base of the skull's petrous bone before exiting to the eye, cheek, and jawbone. But what if this wasn't classical trigeminal neuralgia? What if this was a tumor pressing down on the division of the trigeminal nerve that went to the eye? While this would be highly unusual, it was possible and would produce exactly the sort of pain that Louise was suffering. I hoped that the CT scan would shed some light on my hunch.

A CT scan of the brain makes images by taking pictorial slices, or "cuts," through the brain, beginning at the level of the eye and ear and proceeding upward to the top of the head. It is just as though you were cutting through a watermelon with a sharp knife and making thin slices. Each slice is presented as a cross-sectional image, allowing doctors to actually look into the tissue and see what's inside. Because we know what normal anatomy looks like, we usually notice something that doesn't belong. For Louise's scan, I also ordered a contrast dye, which lights up tumors on imaging and makes them easier to decipher.

Once Louise was given an infusion of morphine, she was whisked in and out of the CT unit with factory precision. The entire study took a minute to perform, and digital pictures were generated on the computer screen in rapid succession. As I carefully studied the images, something caught my eye. The two petrous bones of the skull were not the same. The right petrous bone appeared "moth eaten," as though something were eroding it piecemeal. There was also some contrast seeping into a small area just above the trigeminal ganglion. It looked like a small puff of smoke on the scan, but to me it was more like the smoking gun. This type of contrast filling often indicates a tumor.

"It could be anything," I told myself. "Not necessarily cancer." I put in a request for the radiologist to review the films, and then made my way back to the CT scan holding area to see how Louise was doing on the morphine dose I'd prescribed. She was still lying on her side, wrapped up in a cotton hospital blanket. Her face was buried in the pillow, with most of her makeup rubbed off and her hair lying limply over her cheek.

"Louise?" I put my hand lightly on her shoulder. "Are you all right?"

When she turned to face me, she looked sleepy and drugged. “I’m fine, Dr. Castaldo,” she slurred. “This medicine is really working.”

I picked up her chart. Her blood pressure had dropped to 140/95 and her heart rate had slowed to 70 beats per minute. Both were good news.

“Did you get the Tegretol pills?” I asked, and she nodded. “I’m hoping they’ll start kicking in soon and get you some more relief,” I said. “Meanwhile, I’m going to admit you to the hospital tonight to run some more tests. Shall I call your husband to let him know?”

She nodded again, and then fell fast asleep.

I went back to my office and contacted Louise’s husband, Andy, relaying the most hopeful scenario I could. A few minutes later, I received a page from the radiologist on call. “I just reviewed the CT scan on Louise Marinelli,” he said. “She’s got a tumor or something eating the base of the skull. But I can’t tell what it is.”

Great, I thought. *We do a test and find out nothing we didn’t already know.* “I think we should do some more fine cuts of CT through the area to get a better picture of the region,” he continued. “Fine,” I agreed. “Do it.”

That evening, after a hurried dinner with my wife and sons, I did a computer search of the literature from my home. The only tumor that had ever been reported to infiltrate the trigeminal nerve was a cancer known as lymphoma, a soft tumor that often responds to radiation and chemotherapy. I began to feel a ray of hope for Louise. I’d heard of women developing leukemia or lymphoma as a long-term consequence of chemotherapy given

that has settled itself right on a delicate nerve at the base of your brain."

"Just my luck that a tumor would pick a painful spot to set up housekeeping," she quipped.

I was taken aback at how well Louise seemed to be taking all of this. Momentarily, I wondered if she was in shock or denial. "Well, even if it is a tumor," I said, "we don't know what kind of tumor it is yet, and once we know, there may be some treatment for it." I was careful not to use the word "cancer" again, trying to leave open a door of hope.

But Louise plunged right in. "My oncologist seems pretty certain it's my old breast cancer back for a revisit," she said, looking at me intently. Clearly, she wasn't in denial. "That's not good, is it?"

"No, it's not," I admitted. "But keep in mind that doctors are sometimes wrong." I felt a renewed flash of anger at the oncologist. "Let's move forward with the biopsy so we can be absolutely sure that we're doing everything possible to get a diagnosis."

"So you want to put me through brain surgery, just to be sure?" She cocked her head at me questioningly. "I don't know if I like that. Besides, it might put me right back into the pain I was in when you admitted me."

I started to explain that the biopsy would be done with a minimally invasive technique when she interrupted me. "It's all right, Dr. Castaldo." She was looking at me calmly. "I'm in your hands. If you think a biopsy is best, I'll just salute and do it."

I was humbled by her faith in me. This was her life Louise was placing in my hands. What made her so implicitly trust my decision-making when the stakes were so high? Was it because

I was a neighbor, and a lousy one at that? Or, more likely, had she heard of my reputation as a neurologist, which I assumed was good? Even so, I had more questions for my mechanic when he wanted to change my car's transmission oil than Louise did upon hearing that she needed an operation on her brain. I hoped, mightily, that I was worthy of her trust. The responsibility weighed on my chest like a stone.

Two days later, the tumor was biopsied by a neurosurgeon, utilizing a catheter and a needle that went up through the upper lip, slipped through a natural hole in the base of the skull, and snaked up to the tumor to secure a tiny piece of it. When the pathologist called with the results, I felt myself tensing up.

"I got only a small piece of tissue from the needle biopsy," were his first words. My heart sank: I knew what was coming.

"It could be lymphoma or it could be breast cancer," he went on. "Can't tell."

Desperation seized me. "We did the biopsy to settle the question of breast cancer versus lymphoma, not to restate the question!" I was practically shouting.

"I just can't be certain without doing some stains," the pathologist replied calmly. He was referring to special pathology stains that are developed to bring out certain tissue characteristics more clearly. "Well, *do* them, then," I barked. "We need to settle this!" I couldn't bear to think about having to confront Louise again with the words: "We don't know yet."

Later that day, I sent Louise home on Tegretol, off narcotics, and virtually pain-free. As she got ready to leave the hospital with her husband, she looked healthy and vital, and once again I allowed myself to feel hopeful. I told her to come back to see me in a few weeks to discuss the results of the special pathologic stains, which could take up to two weeks to complete.

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But the special stains did not help differentiate the tumor. So we sent it out to another institution for special immunological fixation. This type of staining is very specific for breast cancer and is considered to be faultless, but it can take up to a month or more to complete. Once again, I had to give Louise the excruciating news: "We still don't know." Even worse: "And we won't know for a while."

Meanwhile, we formulated a plan to give Louise a boost of radiation focused on the trigeminal ganglia. She would be left with a permanently numb face just over the cheekbone and eye, but she would be pain-free and able to wean herself off the Tegretol therapy. With her usual trust and stoicism, Louise agreed to the latest plan.

For the next several weeks, I thought repeatedly of the stains and what they might show—either a death sentence or a blessed reprieve. About a month into this harrowing waiting game, I happened to see the oncologist on rounds. "Have you heard the latest pathology report on Mrs. Marinelli?" I asked him.

"Oh yeah," he said, rather casually. "I got that a couple of days ago." Inwardly, I bristled: He hadn't even bothered to let me know! Then the oncologist smiled; it was an odd, almost triumphant expression. "It's recurrent breast cancer, John," he said, coolly meeting my eyes. "There's really nothing more to do but keep her comfortable."

My stomach turned over; I couldn't speak. So I'd been wrong all along. And wrong in the direction of being overly optimistic—a terrible thing to do to a terminally ill patient. I had given Louise and her family false hopes; I hadn't adequately prepared them for this devastating news.

I called Louise and asked her to come in for an appointment. When I told her the news, she burst into tears. I held her hand, silently. For a while, she just sat in her chair with her head bowed, shaking with sobs. Finally, she looked up at me. "I have two kids at home," she said, almost in a whisper. "What are they going to do without their mommy?"

Soon afterward, Louise began experimental chemotherapy at the suggestion of a specialist at another hospital. Meanwhile, follow-up MRI scanning of the right brachial plexus confirmed that cancer was, indeed, the cause of her progressive arm paralysis. The first three scans hadn't picked up the tumor because at the time they were done, the cancer had been too small. But now it was growing in exponential fashion. When one million cells double to two million overnight, and then two million explode into four million, a cancer mass looks as though it is growing before your very eyes. When I read the MRI report of Louise's plexus cancer, I felt nauseated. Occam had been right: One single diagnosis explained all of my patient's symptoms. Louise had recurrent, aggressive breast cancer, and she was dying from it.

At each of my follow-up visits with her, I tried to hide my own distress. "How are you holding up?" I asked her each time.

Louise's answer was always the same. "I'm doing well," she would say, sounding as though she really meant it. During one visit, she confided that she had never expected to survive her breast