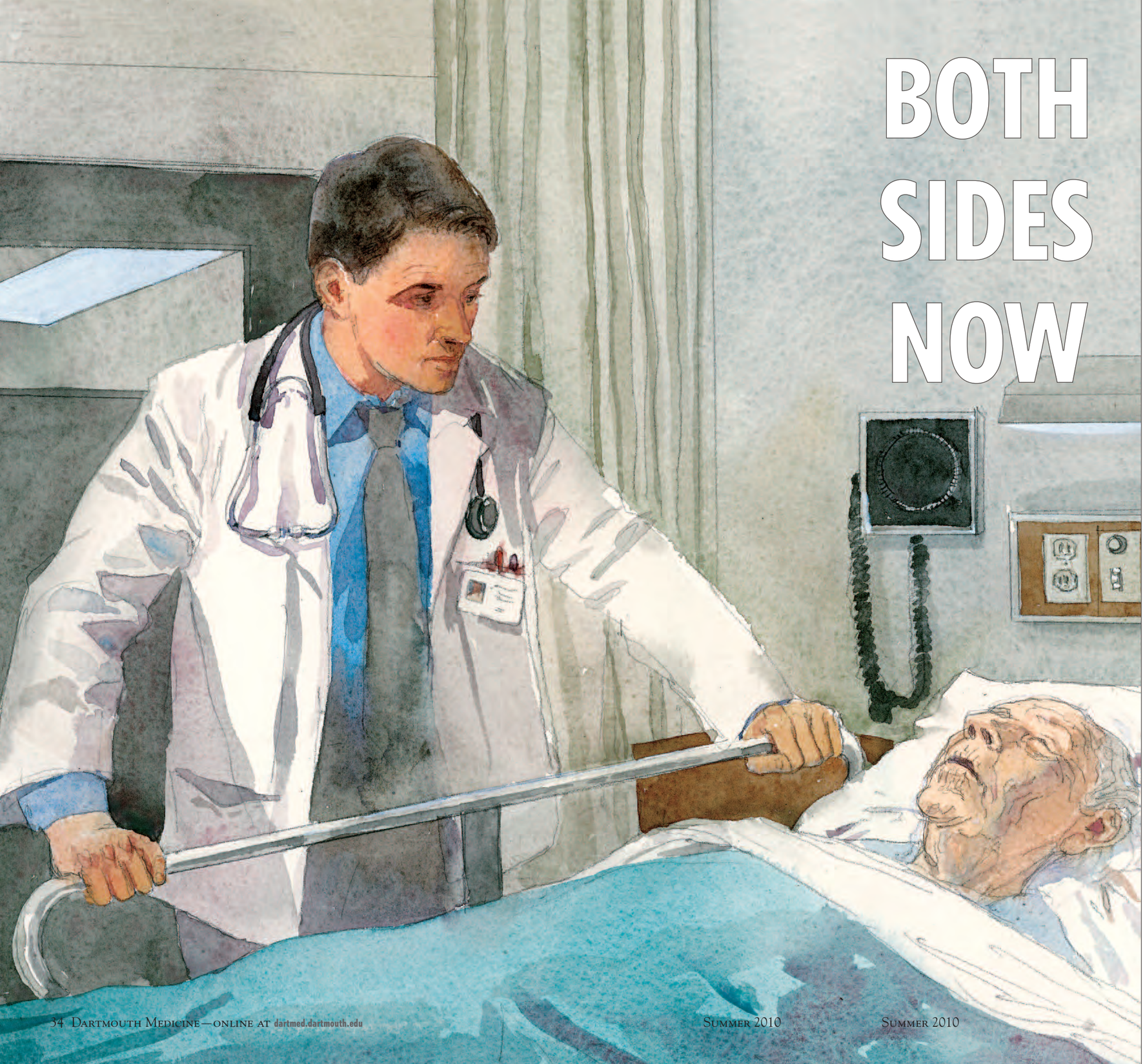

BOTH SIDES NOW

A young physician-in-training at Dartmouth-Hitchcock Medical Center writes about the doctor-patient relationship from the perspective of someone who has experienced both sides of that bond.

Text by Trevor Bayliss, M.D.

Illustration by Bert Dodson

I was leaning over a plastic cart filled with face masks and latex gloves, copying the morning vital signs from a patient's bedside chart, when a nurse came running down the hall.

"17A is in V-tach," she panted as she passed me. Another nurse and an intern—her long white coat flapping, an overflowing clipboard clutched to her chest—followed close on the first nurse's heels. It was a startling break in what had become my predictable morning routine.

A third-year medical student, I was three weeks into my four-week rotation in hospitalist medicine (a specialty whose focus is caring for hospitalized patients) and had finally become efficient at accomplishing my duties. During the first week, I would arrive when it was still dark outside, switch my fleece jacket for my short white coat in the basement locker room, and be on the unit by 5:30 a.m. This left me ample time to flounder through my patients' charts; retrieve their lab values and CT and x-ray reports from the computer; perform my painfully slow and far too thorough physical exams; and write up my notes. I'd usually be done sometime in the late afternoon. Sometimes, my resident would be leaving for the day as I was still struggling through my last note. I would then place it in the patient's chart, where it would most likely remain unread. That didn't particularly bother me, but I did find it ironic because compared to the residents, who didn't have time to write neatly, and the attending physicians, who perhaps had learned over the years to decipher each others' cryptic code, my notes (and those by the nurses) were the only ones that were legible. Of course, the residents had to write notes not only on the patients I was following, but also on half a dozen others. My goal was not to slow them down or get in their way.

But already, by my third week on the service, I had discovered how to streamline my part of the process. I now knew right where to look in the charts for the important information—a good summary of my patients' condition and an up-to-date list of their medications. At the beginning of the rotation, I would then peek timidly into their rooms. If they were sleeping, which they often were at 6:00 a.m., I'd try to find something else to do before checking back later. If they were still sleeping, I'd stand at the door, hoping to catch them stirring so I could walk in and gently wake them. I would often perform my exam in the dim light of dawn, to avoid rudely flipping on the overhead fluorescent lights. But in only three weeks' time, I had shed my

Bayliss is a resident in internal medicine at DHMC. He graduated from Williams College in 1999 and earned his M.D. from Albany Medical College in 2007. Some identifying details about "Mr. Cullen" have been changed to preserve confidentiality.

timid approach for one designed to "get the job done." It was a style I had picked up from the residents—one I now realized was essential to survive, day after day, while caring for a dozen patients.

My resident, Jennifer, gave me no more than three patients at a time. She was kind and always seemed well organized. She wore her black hair in a neat ponytail, and the pockets of her freshly dry-cleaned white coat contained only the essentials: a stethoscope, a pen, a penlight, her pager, and a few neatly folded papers containing important patient data. She frequently would ask how I was doing and if I had any questions. I'd try to think ahead so I'd have an intelligent question ready, to show my interest and sophisticated medical reasoning skills. She would give a quick, partial answer, whatever she could fit into about two minutes, neatly wrapping it up so as not to get behind on her endless list of tasks. She'd always conclude by saying that we would discuss the question further later on, but she would either forget or perhaps hope that I would forget.

Despite her incredibly busy days, she always seemed relaxed but kept to her schedule despite numerous distractions. As the senior resident on the team, she supervised me plus two interns and so had to know all the patients on our service. But even though she'd arrive on the floor an hour later than we got there, she'd already know everything that had come up during the night as well as the details of any overnight admissions. I later learned that the overnight resident passes along any pertinent information to the resident on the next shift, but at the time Jennifer's acumen seemed superhuman.

Occasionally I'd end up with four patients by accident. Jennifer would marvel at my ability to keep up with all four (suggesting that her expectations for medical students were fairly low), then insist that I hand one over to an intern.

Interns are first-year residents. They had two more years of education than I did at that point, and two fewer years of training than Jennifer. It was striking how much confidence only two years of training could confer. In contrast to Jennifer's low-key self-assurance, the interns seemed to wear a constantly glazed look. Like swimmers treading water in choppy surf, they struggled to make the transition from the comforting confines of medical school to the open-ended life of an intern. Some, of course, handled it better than others, but none—including the one who'd just raced past me to Room 17A—had enough time to help teach a medical student.

I had been in 17A just an hour earlier to check on Mr. Cullen, one of "my" three patients. I had performed my routine daily exam. He had asked me if he could have eggs for breakfast. I'd said "Sure." Mr. Cullen was a frail 85-year-old with multiple medical problems. He had a history of lung cancer, chronic obstructive pulmonary disease, hypertension, and chronic heart failure. His medication record was three pages long. The complexity of his case, if not its specifics, exemplified the majority of the patients on our service.

His current hospitalization was due to pneumonia. He had been improving, although he continued to have occasional brief arrhythmias, or irregular heartbeats, so he remained on cardiac monitoring. Sensors on his chest recorded his heart rhythm and sent the information to a lab in another wing of the hospital. The minute a dangerous rhythm occurred, a warning would be transmitted to the floor. Mr. Cullen had had a couple of episodes of very brief ventricular tachycardia (or V-tach), which if brief can be harmless. But if V-tach is sustained, it results in death. I had examined Mr. Cullen each morning for the past week, and this morning was the first time he had answered my questions with more than one-word answers, and he'd even asked about his breakfast.

Now, the two nurses and the intern disappeared into his room, directly across the hall from where I was standing. As I cautiously approached the door, Jennifer brushed past my shoulder and strode to the side of his bed.

"Mr. Cullen," she called out in a loud voice. "Mr. Cullen, can you hear me?" She rubbed his chest vigorously, then reached for his wrist. "He's unresponsive," she observed matter-of-factly. "I can't find a pulse. Someone call the code."

As if on cue, another nurse entered the room and stated, "He's DNR." Do not resuscitate. That meant Mr. Cullen had signed a document saying if his heart stopped pumping, he did not want to be artificially revived.

There was a brief silence—probably only a few seconds, but it felt like minutes. Jennifer looked at the nurse. "Are you sure?" she asked.

"It's right here in his chart," she replied, holding the chart open to the page with the signed DNR document.

Jennifer's expression was one I hadn't seen on her before. For the first time, she seemed uncertain what to do. She glanced at the other nurses in the room and quickly at me standing in the back. She turned back to Mr. Cullen and rubbed his chest again, repeating over and over, "Mr. Cullen . . . Mr. Cullen." With her stethoscope, she listened for heart sounds.

Stuffing the patient notes I had been working on into the pocket of my white coat, I inched closer. The head of Mr. Cullen's bed was raised. His light-blue hospital gown was unbuttoned at both shoulders, exposing his bony chest and protruding clavicles. His skin was a pale, ashen hue, and his wispy gray hair was matted from days of lying in bed. His head was tilted to the right, and his eyes were half-open and fixed on some imaginary spot on the dusky, off-white wall.

As Jennifer helplessly continued to listen for heart sounds, he suddenly inhaled violently, his neck twisting as his chest rose sharply off the bed. Jennifer removed her stethoscope and stepped back, still focused on his chest, trying to hide her startled response. For a moment I thought he was back. My hope came from movies where I'd seen a lifeless victim suddenly revive after a dramatic inhalation. But Mr. Cullen's eyes remained fixed, and his jaw hung slackly. The exhalation that followed was slow, with an audible whisper as the air passed over his blue-tinged lips. Gradually, his chest relaxed and he settled back onto the bed. And then he was silent and lifeless once more.

One of the nurses, the one holding the chart, turned and left the room. Jennifer tried again rubbing Mr. Cullen's sternum, and in a strong tone called, "Mr. Cullen." Nothing. She continued to fidget with her stethoscope. Had Mr. Cullen not been DNR, she would have sprung into action, delivering CPR, running the code. But there is no clear procedure when a patient is dying and no medical interventions are left. To hide their own vulnerability, many doctors leave the room in such situations—rationalizing that their role is done and leaving the end-of-life care to the nurses. But Jennifer remained at Mr. Cullen's bedside.

It seemed like several minutes passed. Another inhalation, this time with a little less force, again pulled his bony chest off the bed. The exhalation was again slow and sustained, but at the end the whisper of air was replaced by a gurgling from deep in Mr. Cullen's throat. I'd heard people in the hospital refer to this noise during someone's final breaths as a "death rattle," but it was the first time I'd actually heard it. It was jarring, like a gruesome movie effect.

Jennifer turned and headed for the door, her eyes on the floor, subtly shaking her head. "Where's the intern?" she murmured. "She needs to start the paperwork."

The last nurse in the room, an older woman, walked to the side of the bed. She lowered the head of the bed, adjusted the pillow, buttoned up the shoulders of Mr. Cullen's hospital gown, and softly touched his shoulder as she turned away. "I'm going to notify his next of kin," she said as she, too, left the room.

I fought my urge to follow her out. It seemed wrong to leave. *No one should be alone in their last minutes of life*, I thought. The room was quiet. I wondered if Mr. Cullen's spirit was leaving his body, if, from above, he was watching me watch him. I half expected a light to appear. His eyes remained fixed, and I wondered if he could see something I could not, something beyond the pale hospital walls. Despite the institutional surroundings, the mood seemed right. Mr. Cullen's wishes were being honored. He was being allowed to die on his own terms.

I ignored the voice that kept telling me to leave and stepped to his side, touched his hand. I suddenly remembered why I was here—in this room, in medical school. Just a few years before, my mother had been where I was now, holding my hand, probably praying that my stare would not turn blank as I focused on something she could not see. I had been Mr. Cullen. I had been a patient. I was still a patient.

My training had already begun, with surgical precision, to erect a wall between my new identity-to-be as a doctor and my experience as a cancer patient. With new understanding, I remembered why I had chosen to go into medicine. In that moment, I vowed that I wouldn't let the divide between doctor and patient harden. As I let go of Mr. Cullen's hand, I said a silent prayer for him and a fervent thank-you for my own continued good health.

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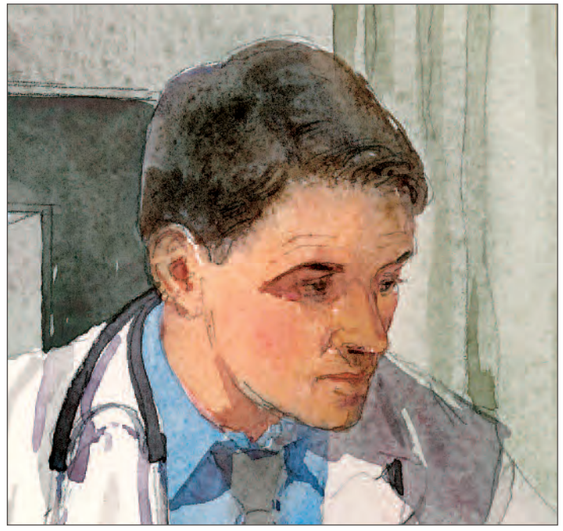
My mother took the phone call that changed my life in July of 1995. I knew it was the doctor from the tone of her voice and from the fact that she disappeared into her bathroom to talk, as I sat watching TV in the living room.

I knew my diagnosis the minute my mother emerged from the bathroom. She wasn't crying—she always put up a strong front—but I could see that her eyes were red. She paused and looked at me on the couch. "You have cancer," she said. I don't remember what she said after that, but I do remember what I felt, and it surprised me: relief. Anger and fear would take their turns, but in that moment I felt relief. The diagnosis finally offered a concrete explanation for my persistent fatigue. I had just finished my freshman year at Williams College, in my hometown. I had struggled in both ice hockey and track and field, sports in which I'd always done well. At first I thought I was simply burned out and needed a break from athletics. But as the summer passed, I simply could not get into shape. Every workout was a struggle. And I was exhausted at the end of each day at my summer job with the college buildings and grounds department.

Also over the course of that spring and summer, my stomach had been getting progressively bigger. But my mind found a way to ignore the change even as it was becoming ever more obvious to others. In late April, I had walked out of the changing room in my swimming shorts onto the pool deck for a water workout with the track team. As I approached my coach, he called out in a voice just loud enough for everyone to hear, "You look like



you're pregnant." It turns out I was, only my baby was a 10-pound spleen that came out in early August. I still recall the sense of pride that penetrated my postop morphine haze when my surgeon told me it was the largest spleen he had ever removed.

The concept of "watch and wait"—which was what came next—was a difficult one for me to grasp. I had cancer, but it did not require treatment after my spleen was removed. As my sophomore year passed, I attempted to return to normalcy, only to gradually discover that normalcy for me had forever changed. I went to college parties but felt out of place. My mind easily wandered from my studies. In an effort to gain some control over my illness, I took to meditation, visualization, and other alternative therapies as a way to give my body any possible edge in ridding itself of this smoldering disease.

As time passed, I became mentally stronger and began to feel comfortable with the idea of living with cancer. Midway through my junior year, however, I found myself sitting at the top of a flight of stairs completely out of breath and lightheaded. And people had begun to comment on the purple hue of my lips and fingernails. A biopsy confirmed that cancer cells were infiltrating my lungs. I had a relatively rare form of leukemia called T-cell LGL (for "large granular lymphocytic") lymphoma.

And my case was unusually rare. First, the median age of diagnosis for the disease is 60, and I was in my early 20s. Second, LGL cancers are typically indolent, or slow-growing, though a very small subset of cases present as an aggressive and hard-to-treat illness. My case was breaking all the rules by transitioning from indolent to aggressive. I was in uncharted waters.

It took me a while to absorb the implications of "aggressive." I was caught off guard when my hematologist announced, "We need to start chemotherapy immediately." In my mind, "immediately" meant within a month. In his, it meant tomorrow. We compromised on a week.

Despite the treatment's harsh acronym—CHOP, shorthand for a combination of four drugs—my chemotherapy went smoothly. I was feverish for a day or two after each cycle and felt some overall fatigue but experienced no nausea or vomiting. I managed to continue taking a couple of classes and avoided any hospital admissions.

The next step in my treatment plan was far more disruptive. At 4:00 a.m. on a mid-March morning in 1997, my mom and I woke up and headed out in the dark to catch a flight across the country. We were headed for the Fred Hutchinson Cancer Research Center in Seattle, Wash., where I was scheduled to receive a bone marrow transplant—the best shot that I had at recovery, according to my doctors. My family had been tested but none of them were a suitable match. However, through the national bone marrow registry, an anonymous donor had been identified. So a stranger's bone marrow stem cells would "reboot" my immune system after the intensive, high-dose chemotherapy that was deemed the only thing able to destroy the cancer cells that had infiltrated my body.

In Seattle, my mother and I settled into a small apartment two blocks from the cancer center. On our second day there, I had a Hickman catheter placed in my chest. It tunneled just beneath the skin for about two inches, then dove down close to my collar bone and entered my left subclavian vein. From there, the catheter tip extended into my superior vena cava and rested close to the entrance to my heart, where drugs could be delivered and blood drawn. From the skin surface, several inches of tubing dangled, which I flushed twice a day and kept taped to my body when the port wasn't in use.

A few days later, my new doctors told me that I needed to be on continuous oxygen. A large oxygen machine was delivered to the apartment, and I was also given a portable unit as well as a stern lecture from my doctor the first couple of times I came to the hospital without it. After that, I would sling the unit over my shoulder and make sure I put the prongs in my nose before I passed through the cancer center doors.

The pre-transplant chemotherapy was more intense than my previous regimen had been. My fatigue entered a new dimension. And with the physical fatigue came mental fatigue. I spent hours on the couch watching TV and drifting in and out of sleep. I tried a couple of times to use the stationary bike at the apartment complex gym, pedaling slowly on virtually no resistance for 10 minutes or so. It was exhausting, but it made me feel like I was doing at least a little to help my body stay strong.

As the chemo schedule neared its end, I got a tour of the radiation room where I would receive whole body radiation to "zap" all the cancer infecting my bone marrow, and of the hospital floor where I would stay while my new bone marrow engrafted and my immune system regenerated.

One evening after dinner, we got a phone call asking us to come over to the hospital. My labs from earlier that day had been reviewed and my platelet level found to be dangerously high. The doctor was concerned about spontaneous clots. So my Hickman catheter was hooked up to a machine, and I spent the evening watching my blood leave my body, enter a plasmapheresis machine where some of the platelets were filtered out, and then return to my body.

Over the next few days, I underwent a couple more bone marrow biopsies and almost daily blood draws—several tubes a day. I wondered how my blood production system kept up with the assault. My body was taking a beating, but overall I felt like I was holding my own.

A week before my transplant, my mother and I were scheduled to meet with my doctor. We waited in a small, quiet conference room off a busy hall. The door swung open and the doctor entered the room. She offered a brief hello and sat at the table across from me. I knew the reason for the meeting was so she could summarize the results of all my tests and detail the steps leading to the transplant. But in the pause before she started to speak, I knew there was going to be a twist. She launched into the results of my most recent bone marrow biopsy, explaining that my low blood oxygen level meant that disease remained in my lungs. Finally, she arrived at her point: "With the involvement of the lungs and your recent desensitization to the chemotherapy, there is a 95-percent chance that you would die from the transplant itself. There is little else we can do."

The silence in the room lasted only a few seconds, but it felt like an eternity. The doctor stumbled through some more explanations about my lack of response to the chemotherapy and the continued involvement of my lungs. She mentioned the possibility of changing to a different high-dose chemotherapy but said the likelihood of my responding to it was almost nil.

I remember thinking, *How can there be a 95-percent chance I'll die?* I would either die or I wouldn't. I think my mother asked a question. I felt foggy and fought down a knot in my throat. I had shed some tears since that July 1995 phone call, but mostly when I was alone and mostly in the time shortly after my diagnosis. I'd had one unexpected breakdown in Seattle about a week earlier, during a mandatory meeting with a social worker. I was physically and mentally fatigued, and when she started pushing and prying about my parents' divorce eight years earlier, I was unprepared for the bottled-up emotions that surfaced. I knew this time that I had about one sentence in me before my voice would crack and tears would flow, so I asked, "In your medical opinion, how long do I have to live?"

She replied, "Without treatment?" as if that mattered.

"Yes." One word was all I had this time.

"Weeks to months."

I had dealt with predictions and percentages throughout my journey with cancer and understood that they were all averages derived from groups of similar patients—since each individual patient obviously lives for a set time. When the data are plotted out, they represent a bell-shaped curve, with a small portion to the right living longer than average and a small portion to the left living shorter. We don't really understand what factors place people on the extremes of the bell curve. Perhaps it's the biology of their cancer cells, or perhaps certain personality or attitude traits. I tended to hold to the latter view and believed that if I faced my illness forthrightly, meditated, visualized, and fought, I'd be among those who lived longer than average.

Some doctors stayed away from statistics, and I preferred that even more. The ones who used statistics wanted to place me right on the average and test my hope at each appointment. I understood that it was their duty to let patients know what they faced. I was even able to admit that my hope at times bordered on denial. But denial and hope are closely linked and, I think, often blur together.

That night in bed was the first time I allowed myself to think that this disease could take my life, that I might die young. I never accepted that I might die in weeks. I just didn't see how that could be, based on how I felt. I had a strong, young heart. And though I was getting some supplemental oxygen, I didn't feel short of breath. What would it be like to die because I couldn't breathe? Could I get to that point in just a few weeks? Or maybe I would develop an overwhelming infection because of my depleted immune system. It was hard to imagine that, however. Except for my splenectomy, I hadn't been hospitalized once.

As I cried myself to sleep that night, my tears had a paradoxical effect—they washed away my fear. At the time, I wasn't sure what was happening. *Maybe I'm just becoming numb to it all*, I thought. *Or entering another phase of denial. Or on the verge of going crazy*. But in retrospect, I have realized that that night was the first time I accepted the fact that my illness had a momentum all its own. It controlled me, I didn't control it.

Over the next two days, my mom packed up our things. On the third day, we were on a plane again (I dutifully carrying a portable oxygen tank), heading east, without the transplant that was supposed to save my life.

When I arrived home in western Massachusetts in late April, there was an oxygen tank waiting for me in the living room. But I was also surrounded by family and friends; I felt comfortable and stronger almost immediately. The week I got back I had an appointment with my doctor. I related what had transpired in Seattle and the prognosis I had been given. His response, after a pause, was, "You don't look that sick."

It was the perfect reply. I didn't *feel* that sick. I didn't need to hear a recitation of the technical details of my health status. I needed a little hope and a few fresh options. My doctor had learned of some patients with T-cell LGL lymphoma who were doing

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well on a low-dose oral chemotherapy drug, methotrexate. He laid out three other options: a different high-dose chemo regimen, like the one they'd offered in Seattle; an experimental chemotherapy with little track record; and, finally, no treatment at all.

I had had enough of high-dose chemo. But I wasn't ready to settle for nothing. The low-dose methotrexate sounded like the best option, especially since it promised little in the way of side effects. I started on it, along with oral steroids. The response was quick. Within weeks, I was feeling better and was able to get off oxygen. After two months, I had tapered off of the steroids. And at three months, the cancer cells were virtually undetectable in my blood.

As the years have passed, I have become more and more accustomed to being the one delivering the care instead of receiving it. The one wearing the white coat instead of between the white sheets. But I still remember what it felt like to face death. I sometimes think, as I did at Mr. Cullen's bedside, *That could have been me*.

I hope never to lose the ability to look at my patients' struggles through their eyes. ■

Map Quest

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and reward high-quality care? These questions need to be addressed as the U.S. healthcare system begins to wrestle with timetables in the new health-care reform legislation.

Still, the bottom line is that we believe there is enormous scope for improving the efficiency and quality of U.S. health care. The Dartmouth research suggests that improvements in both cost and quality can be achieved through the development of new models of payment that reward providers for improving quality, managing capacity wisely, and reducing unnecessary care.

More information on this research is available on the *Atlas* website. In addition, Dartmouth Medicine has often covered the findings of the *Atlas* researchers. Links to past articles on the subject, and to the *Atlas* website, are at **dartmed.dartmouth.edu/su10/we01**. ■