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[By Kenneth B. Schwartz]

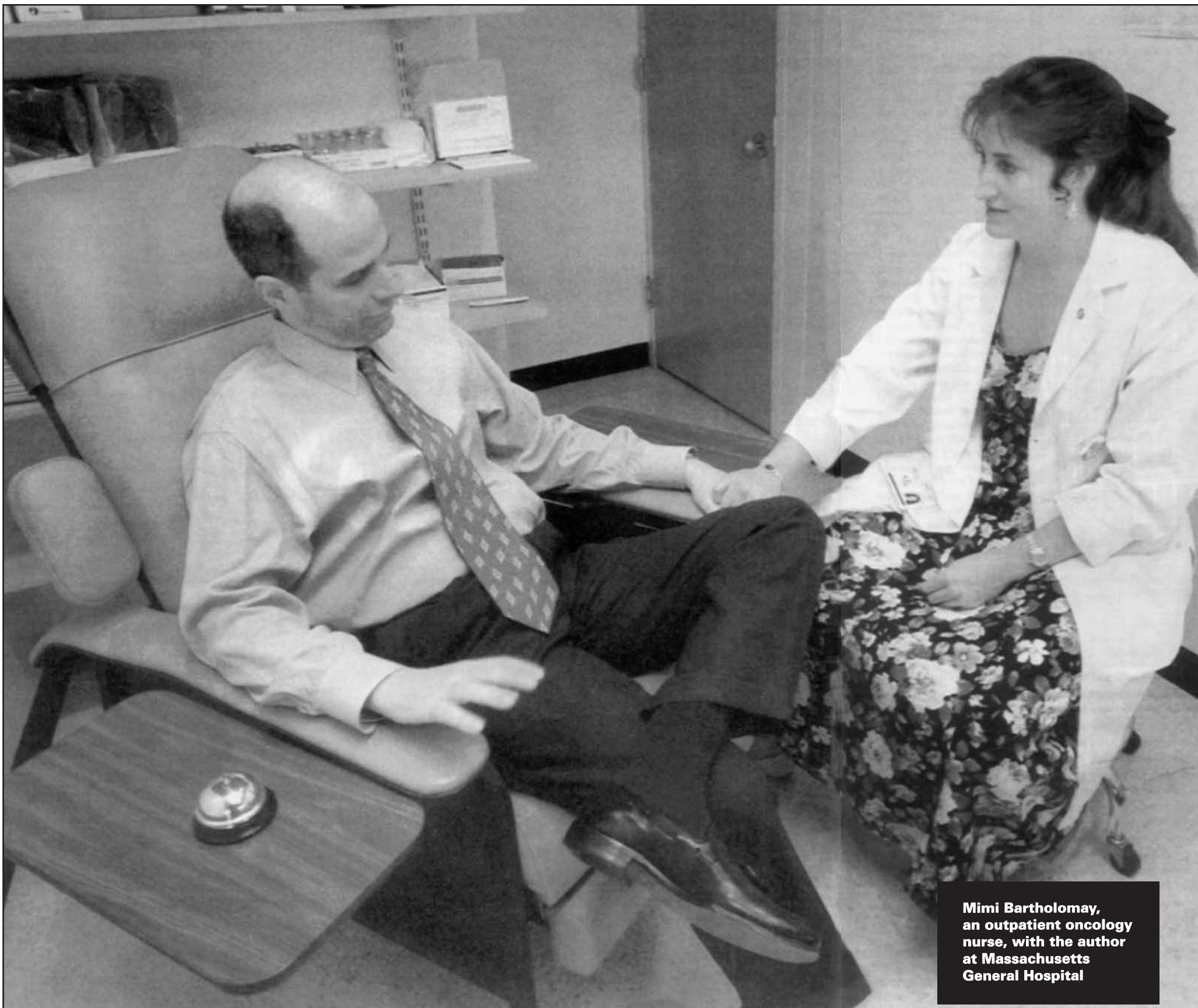
UNTIL LAST FALL, I had spent a considerable part of my career as a health-care lawyer, first in state government and then in the private sector. I came to know a lot about health-care policy and management, government regulations and contracts. But I knew little about the delivery of care. All that changed on November 7, 1994, when, at age

A PATIENT'S STORY

40 I was diagnosed with advanced lung cancer. In the months that followed, I was subjected to chemotherapy, radiation, surgery, and news of all kinds, most of it bad. It has been a harrowing experience for me and for my family. And yet, the ordeal has been punctuated by moments of exquisite compassion. I have been the recipient of an extraordinary array of human and humane responses to my plight. These acts of kindness – the simple human touch from my caregivers – have made the unbearable bearable.



The author (seated) with Dr. Thomas Lynch, an oncologist at Massachusetts General Hospital.



**Mimi Bartholomay,
an outpatient oncology
nurse, with the author
at Massachusetts
General Hospital**

photography by Bill Greene / The Boston Globe

A PATIENT'S STORY

BY KENNETH B. SCHWARTZ

During September and October of 1994, I made several visits to the outpatient clinic of a Boston teaching hospital for treatment of a persistent cough, low-grade fever, malaise, and weakness. The nurse practitioner diagnosed me as having atypical pneumonia and prescribed an antibiotic. Despite continued abnormal blood counts, she assured me that I had a post-viral infection and didn't need an appointment with my physician until mid-November, if then. By mid-October, I felt so bad that I decided I could not wait until November 11 to be seen. Disappointed with the inaccessibility of my physician, I decided to seek care elsewhere, with the hope that a new doctor might be more responsive.

My brother, a physician who had trained at Massachusetts General Hospital, arranged for an immediate appointment with Dr. Jose Vega, an experienced internist affiliated with MGH. Dr. Vega spent an hour with me and ordered tests, including a chest X-ray. He called within hours to say he was concerned by the results, which showed a "mass" in my right lung, and he ordered a computerized tomography scan for more detail. I remember leaving my office for home, saying quickly to my secretary, Sharyn Wallace, "I think I may have a serious medical problem." Indeed, the CT scan confirmed abnormal developments in my right lung and chest nodes.

The next day, Dr. Vega, assuring me that he would continue to be available to me whenever I needed him, referred me to Dr. Thomas Lynch, a 34-year-old MGH oncologist specializing in lung cancer. Dr. Lynch, who seems driven by the ferocity of the disease he sees every day, told me that I had lung cancer, lymphoma, or some rare lung infection, although it was most likely lung cancer.

My family and I were terrified. For the next several months, my blood pressure, which used to be a normal 124 over 78, went to 150 over 100, and my heart rate, which used to be a low 48, ran around 100.

Within 72 hours of seeing Dr. Lynch, I was scheduled for a bronchoscopy and a mediastinoscopy, exploratory surgical procedures to confirm whether I indeed had lung cancer. Until this point, I had thought that I was at low risk for cancer: I was relatively young, I did not smoke (although I had smoked about a cigarette a day in college and in law school and for several years after that), I worked out every day, and I avoided fatty foods.

The day before surgery, I was scheduled to have a series of tests. The presurgery area of the hospital was mobbed, and the nurses seemed harried. Eventually, a nurse who was to conduct a presurgical interview called my name. Already apprehensive, I was breathing hard.

The nurse was cool and brusque, as if I were just another faceless patient. But once the interview began, and I told her that I had just learned that I probably had advanced lung cancer, she softened, took my hand, and asked how I was doing. We talked about my 2-year-old son, Ben, and she mentioned that her nephew was named Ben. By the end of our conversation, she was wiping tears from her eyes and saying that while she normally was not on the surgical floor, she would come see me before the surgery. Sure enough, the following day, while I was waiting to be wheeled into surgery, she came by, held my hand, and, with moist eyes, wished me luck.

This small gesture was powerful; my apprehension gave way to a much-needed moment of calm. Looking back, I realize that in a high-volume setting, the high-pressure atmosphere tends to stifle a caregiver’s inherent compassion and humanity. But the briefest pause in the frenetic pace can bring out the best in a caregiver and do much for a terrified patient.

The nurse left, and my apprehension mounted. An hour later, I was wheeled to surgery for a biopsy of the chest nodes and the mass in my lung. I was greeted by a resident in anesthesiology, Dr. Debra Reich, who took my pulse and blood pressure and said gently, “You’re pretty nervous, huh?” She medicated me with tranquilizers, but that did not stop me from asking about where she lived, where she had trained, and whether she was married. I jokingly asked her how come she was the only Jewish doctor I had met during

The best medicine

IN MY NEW ROLE AS PATIENT, I have learned that medicine is not merely about performing tests or surgeries, or administering drugs. These functions, important as they are, are just the beginning. For as skilled and knowledgeable as my caregivers are, what matters most is that they have empathized with me in a way that gives me hope and makes me feel like a human being, not just an illness. Again and again, I have been touched by the smallest kind gestures — a squeeze of my hand, a gentle touch, a reassuring word. In some ways, these quiet acts of humanity have felt more healing than the high-dose radiation and chemotherapy that hold the hope of a cure.

I deeply appreciate the care I have had as a patient. But I can’t help wonder why I have had such a heartening experience. Is it attributable to the exceptional quality of care and caring delivered at Massachusetts General Hospital? Is it due to the particular caregivers that I happened to meet? Or have I benefited in some way from my family’s medical connections, since my father and brother were trained in Boston academic institutions and have ties to senior MGH physicians? Perhaps my experience has not been the result of happenstance or special relationships but of a health-care environment that still places the patient ahead of the bottom line.

If so, for how long will such a compassionate approach endure? Medicaid and Medicare cuts, both present and future, will have devastating effects on hospital care. Managed care is already making its mark in

closed and there seemed to be a lot of activity, so I decided not to disturb you.

“As I’m sure you know, we as physicians are taught not to become emotionally involved in our patients because then we would be continually devastated. But I guess because we had such a nice interaction before your surgery and because your life was one which I could relate to so well — being Jewish, professional, renovating a house, sandwiches at Virginia’s, etc. — your situation really struck a chord in me. (Hey, maybe you can’t even remember any of this because of the medicine I gave you, but hopefully you do . . .)

“I was very impressed that during the fear and anxiety you were experiencing, you still maintained your composure, your sense of humor, and even thought to ask

Massachusetts, and it will only accelerate implementation of its cardinal principles: efficiency, conservation of time and resources, and budget cuts. And now, for-profit insurers and large national hospital chains are trying to penetrate Massachusetts for the first time. In such a cost-conscious world, with its inevitable reductions in staff and morale, can any hospital continue to nurture those precious moments of engagement between patient and caregiver that provide hope to the patient and vital support to the healing process?

Time is a prerequisite for real engagement between caregiver and patient. Even the most compassionate caregivers cannot use their healing gifts if they don’t have the time to do so. A friend who worked at the National Cancer Institute, in Maryland, quoted his mentor as saying that when physicians give bad news to a patient, they must give that person more of their time — to explain, to answer questions, and to provide comfort.

Time alone is not enough, however. Caregivers need to be trained and encouraged to engage with their patients. My understanding is that medical-school training now emphasizes to a greater degree the importance of the physician-patient relationship, a bond that ultimately reaffirms the humanity of both. As an eminent Harvard Medical School professor, himself a cancer patient, once taught: “The secret of the care of the patient is caring for the patient.”

— KENNETH B. SCHWARTZ

me when I was getting married.

“So, anyway, as you told me, keeping your wife and son in mind will make you fight strong, and I know this to be true! I know that you have a very loving and supportive family who will help you through this as well.

“Best wishes, and maybe I’ll run into you sometime at Virginia’s.”

I had not forgotten Dr. Reich, nor will I ever forget her willingness to cross the professional barrier, hold my hand, and write those words.

IT WAS CLEAR THAT I WOULD soon begin a new chapter in my illness and undergo the classic treatment for such advanced cancer: intensive chemotherapy and radiation, followed by surgery to remove

the tumors, nodes, and entire lung, if necessary. Dr. Lynch told me that this option presented the real possibility of a cure.

Over the next week, I had a series of additional radiologic scans to determine if the cancer had spread beyond my chest. These scans are incredibly scary: You are placed in a tube resembling a sarcophagus, with only 6 inches between you and the walls, and you may spend several hours inside, deafened by the clanging machine. And the scans always raise fears about whether more bad news is around the corner.

Dr. Vega or Dr. Lynch always made it a point, though, to relay results within 24 hours, so my family and I didn't have to endure the anxiety of uncertainty any longer than necessary.

The scans of my body, head, liver, bones and back were clear. I was relieved.

The doctors soon began an intensive regimen of chemotherapy and radiation, with the goal of destroying the cancer and preparing for surgery to remove my lung.

Before being admitted for my first five-day course of chemotherapy, I had a radiation-simulation session. During such sessions, therapists meticulously map their targets by marking your skin where the radiation should be directed. I was asked to lie on a table in a large, cold chamber. The radiation therapist, Julie Sullivan, offered me a blanket and, mentioning that the staff had a tape deck, asked if I had any requests: I recalled my college days and asked for James Taylor. Listening to “Sweet Baby James” and “Fire and Rain,” I thought back to a time when the most serious problem I faced was being jilted by a girlfriend, and tears ran down my cheeks. As therapists came and went, Julie Sullivan held my hand and asked me if I was OK. I thanked her for her gentleness.

After having a Port-o-Cath implanted in my chest — a device that allows chemotherapy to be administered without constant needle sticks in the arm — I was admitted to MGH in mid-November. During that and other hospitalizations, either my mother or sister would stay overnight, often sleeping in cramped chairs. When I awoke at night in an anxious sweat or nauseated, I would see one of them and feel reassured.

While doctors managed my medical care, my day-to-day quality of life and comfort were in the hands of two or three nurses. These nurses showed competence and pride in their work, but they also took a personal interest in me. It gave me an enormous boost, and while I do not believe that hope and comfort alone can overcome cancer, it certainly made a huge difference to me during my time in the hospital.

During the period between my two

chemotherapies, when I also received high-dose radiation twice a day, I came to know a most exceptional caregiver, the outpatient oncology nurse Mimi Bartholomay. An eight-year veteran who had experienced cancer in her own family, she was smart, upbeat, and compassionate. I had to receive fluids intravenously every day at the clinic, and while there we talked regularly about life, cancer, marriage, and children. She too was willing to cross that professional Rubicon — to reach out and talk about my fear of dying or, even worse, my fear of not living out my life, of not biking through the hills of Concord and Weston on summer weekends with my brother, of not seeing my child grow up, of not holding my wife in my arms. And she took the risk of talking about her own father’s recent bout with cancer. I cannot emphasize enough how meaningful it was to me when caregivers revealed something about themselves that made a personal connection to my plight. It made me feel much less lonely. The rule books, I’m sure, frown on such intimate engagement between caregiver and patient. But maybe it’s time to rewrite them.

AFTER MY SECOND ROUND OF chemotherapy, I was ready for the final stage of what we hoped would be a cure: surgery. Before this could happen, Dr. Lynch repeated my radiologic scans, to be sure that the cancer had not spread. He assured me that the chance of any such metastasis was remote — less than 5 percent — although it would be a disaster if it occurred.

The scans were endless, scary, and lonely. While members of my family stayed with me in the waiting rooms, they could not accompany me to the scanning rooms; the experience again was harrowing. But I felt my greatest fear while awaiting the results. After a week of tests, I had one last scan of my bones. I was concerned when the technologist asked to

do a special scan of my back that had not been done before.

The next day, I called Dr. Lynch’s office and asked his assistant, Mary Ellen Rousell, when I could come in to find out the results. She said, “How about this afternoon?” and then added, “You might want to bring someone.” My heart skipped. When my wife and I entered Dr. Lynch’s office and saw his face, our hearts

sank. He was ashen. He said that while all the other scans were clear, there appeared to be a metastatic tumor in my spine. He explained that this meant that lung surgery at this point would be futile, since other metastases were likely to surface.

Dr. Lynch said that he could not be 100 percent certain that this was a tumor and that, because so much was at stake, we should do a biopsy. My wife and I wept openly — in part, because, looking at Dr. Lynch’s face, we felt that he had lost hope.

I could not help but ask what treatment options were available, and he mentioned a drug called Taxol. Still being the lawyer, I quizzed him:

Me: What is the percentage of people who benefit from Taxol?

Dr. Lynch: Forty percent

Me: How much do they benefit?

Dr. Lynch: They can get several years of life, although it is not a cure. And the median survival for patients on Taxol with your advanced stage of disease is nine months.

Nine months! My wife and I cringed. I

ended the session by asking Dr. Lynch, “How do you do this work?” And he answered, in genuine pain, “By praying that I don’t have days like today.”

I

BEGAN TO HAVE TROUBLE sleeping, and when I awoke, I was filled with dread and despair. I thought frequently of the observation of Richard Block, the founder of H&R Block, who

“The rule books, I’m sure, frown on such intimate engagement between caregiver and patient. But maybe it’s time to rewrite them.”

had survived lung cancer after being told initially that he had only months to live: “I lived for five days without hope and ... my life during those five days ... was far worse than at any time during the ‘horrible’ ordeal of tests or treatments.”

And when I contemplated not living to see my son grow up or not cherishing my wife for a lifetime, I thought of King Lear, who, at a low point, wailed:

*I am bound
Upon a wheel of fire, that mine
own tears
Do scald like molten lead.*

I desperately needed to regain hope, and I needed Dr. Lynch to regain his sense of hope.

A few days later, I had the biopsy. Dr. Lynch met with my family to report that, indeed, after considerable searching, the pathologist had found small deposits of adenocarcinoma in my vertebra. It was now confirmed that I had metastatic lung cancer. Although my brother and my

father, who is also a physician, raised the possibility of radical surgery on my back and lung to remove all the tumors, Dr. Lynch and the surgeons rejected this option because further metastases were likely to appear, and the surgery would be debilitating and reduce my quality of life at a time when my life could well be substantially shortened.

The clear treatment was more chemotherapy. Dr. Lynch again recommended the use of Taxol, with the hope of slowing the cancer’s spread.

My wife and I were largely silent during the medical discussion. I asked my father and brother to leave so my wife and I could talk not facts and figures but matters of the heart. When they had left, I said to Dr. Lynch, “You told me two things all along: One, that you were aiming for a total cure and if that were not feasible, you would tell me at that time. And two, you would never, ever give up on me, never stop trying to fight, to extend my life as long as possible. Am I no longer on the cure route?”

He looked somberly at us and explained that there were no known treatments to cure this stage of cancer.

“And will you stick by me and fight to the end?” I asked.

He nodded vigorously and then outlined a number of state-of-the-art, experimental protocols from which I might benefit after Taxol.

And, leaving statistics behind, he talked of several patients who had defied the odds and lived for years beyond expectations. He advised that my goal should be to be here the same time next year, and then the year after, and the year after — one day at a time, one month at a time, one year at a time. He mentioned several breast-cancer patients who had told him that they had relished their final years with their children in a way that they had never known before. It felt good to leave the medical talk and speak heart to heart, and

it felt to me that he had regained a sense of hope — not for some magical cure but for the possibility of extending my life.

It was crucial to my wife and to me that he not give up hope. I understood his surprise and disappointment at the metastasis; in fact, as one friend suggested, his distress at that event was a sign of his caring about me and his involvement with my case. But we desperately needed him to give us a realistic basis for hope — and he had.

THE NEXT DAY, I BEGAN A NEW chapter in my fight. And once again, Mimi Bartholomay was by my side, monitoring my reaction and assuring me that most people tolerated Taxol very well. I had no allergic reactions, and I felt good that the battle was under way. I had hoped that maybe this could buy me time.

Time was now my best friend, since it could allow medical research to advance and doctors to find new strategies and maybe even a cure for advanced lung cancer.

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During this period, with help from my father, who has had a long and distinguished career in academic medicine, I began to explore potential cutting-edge protocols that could supplement or follow Taxol.

My father arranged a meeting for my wife and me with Dr. Kurt J. Isselbacher, a distinguished researcher and director of the MGH Cancer Center. He is a small man with a large presence and piercing blue eyes, and he was surrounded by

medical books, papers, and many pictures of his family. He was upbeat, telling us of protocols under way that showed promise in fighting metastatic tumors. Like several others, he told me a personal story that cut to the bone: A close family member, he said, had been diagnosed with advanced cancer, which the attending oncologist had said was “very, very bad.” The family member had said to him: “Kurt, you have helped so many people in your life, can you now help me?” He personally treated the family member in that person’s home with chemotherapy, and, 21 years later, that person is thriving.

Dr. Isselbacher offered to serve as an advocate for me, to work with my father and Dr. Lynch to find the most promising protocols. I told him at the meeting that while I had no illusions, I was deeply moved by his refusal to give up and by his abiding hope; I was especially affected because such hopefulness was not coming from a faith healer but a distinguished researcher. He had strengthened our resolve to fight.

As I grappled to maintain my hope in the face of the advancing disease, I was referred to Dr. Ned Cassem, a senior MGH psychiatrist who not only had had vast experience with the seriously ill but was himself a Jesuit priest. I had met with him once during my second hospitalization, and my memory through the haze was that he was the first person with whom I had discussed death. I remembered that when I asked him if, when, and how I should say

goodbye to people, he said, “You know, you don’t have to wait to say goodbye; you can express your love and appreciation for people right now, every day.”

After the devastating news of the metastasis, I felt the urge to seek out Dr. Cassem again, in part to ask if there was anything more I should be doing to help my son, Ben, cope with my illness or the eventuality of my death. I mentioned that several people had suggested I make a videotape for Ben but that I thought I couldn’t do that. Dr. Cassem replied that every time we played or laughed together, we were creating building blocks, precious memories that will be a part of him forever.

I also asked him if he thought I should be doing more to prepare for the possibility of an early death. He looked perplexed and asked, “Have you prepared your will?” I said yes. “Are your affairs otherwise in order?” I again said yes. “So it sounds like you are prepared. ... Remember, death is a minor matter. Living ... that’s the challenge.”

I then told him of the paradox that moments of great pleasure — playing with my son, snuggling with my wife, talking intensely with friends — also caused me great pain and tears. Was I depressed? Was this something to worry about? He looked at me thoughtfully and said: “When you cry about your son, it’s because he has touched you deeply. It’s an affirmation of your love for him. When you weep about the joy you experienced with your wife or close friends, that’s an acknowledgment of your love for them. That’s not a bad thing. ... Maybe a day without tears has been a dull day.” I nodded and then could not help but ask: “Do you believe in the power of prayer?” Dr. Cassem nodded. “Absolutely,” he said, “and your name is on my prayer list.” I felt warmed in his presence, by his wisdom, his common sense, and his spirituality.

IN RECENT MONTHS, I HAVE HAD several setbacks: a bone scan that showed four to five additional tumors, and a CT scan that showed significant progression of the cancer in both lungs. The only good news was that it had not spread to my head or liver. I am pained, but not surprised, at the relentlessness of the disease, and I am straining to retain hope that one of the experimental treatments may succeed where chemotherapy has failed.

Around the time of the CT scan, when I was feeling particularly dejected, I had an appointment with Mimi Bartholomay for an injection. She was running late, and as she approached me in the clinic waiting room, she looked harried. But as she got closer, she could see how unhappy I was and she put her arm around me and directed me to a private room. I began to cry, and she intuitively responded: “You know, scan days are the worst. But whatever

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For the first time, I recently mentioned to Dr. Lynch the idea of a hospice service and wondered how I might reduce future pain as the cancer progresses. Dr. Lynch answered that we were still a long way from that discussion, that we still had many avenues to explore, and that he remained as committed as ever to doing whatever he could to extend my life in a quality way.

the results, we are not going to give up on you. We’re going to fight with you and for you all the way.” I hugged her and thanked her for hanging in there with me.

If I have learned anything, it is that we never know when, how, or whom a serious illness will strike. If and when it does, each one of us wants not simply the best possible care for our body but for our whole being.

I still am bound upon Lear’s wheel of fire, but the love and devotion of my family and friends, and the deep caring and engagement of my caregivers, have been a tonic for my soul and have helped to take some of the sting from my scalding tears.

Kenneth B. Schwartz died of lung cancer in September 1995. Shortly before his death he founded the Kenneth B. Schwartz Center at Massachusetts General Hospital which is dedicated to strengthening the relationship between patients and caregivers. If you would like more information about the Schwartz Center, please call 617-724-4746 or visit www.theschwartzcenter.org