

## **On the Verge**

My appointment with Dr. Moore is for Friday, May 7, at 4:30. On our way to the East Side, David and I talk about the money we are spending on cabs. He suggests that I not worry and consider these costs part of my medical expenses. An hour each way on buses to my appointments would do me in. When I had Hodgkin's disease, I traveled daily from Cambridge to Boston in a jitney that transported students from Harvard Yard, across the bridge over the Charles River, and into Boston to the Medical School. Generally I waited forty minutes for the bus and then tried not to vomit during the bouncy ride. From the bus I walked one-half mile across the Medical School

campus to the hospital. In the waiting room of the radiology department, I waited for as long as three hours. Doing this five days a week for twelve weeks of radiation treatments was equivalent to holding a part-time job. How do people with full-time jobs, families, cancer, and little money possibly manage?

The grapevine reports that Dr. Moore is wonderful. I worried whether she would have time to see me, and I imagine she is accommodating me out of deference to Dr. Cody. Of course, she would probably see me without his referral—I must like the idea that they're taking care of me together.

David and I find our way to her office in New York Hospital and enter a rather nondescript waiting room where I give my name to the receptionist. A few old magazines are scattered about; a bulletin board is filled with notices about events relating to breast cancer. A hall leads to a number of offices, but it seems that exchanges between doctors, technicians, and secretaries happen very much out in the open here. A central space is crowded with desks, each stacked high with papers. Patients pass through and chat with the staff. I feel less like being on a blind date here than waiting to be adopted.

Soon a lively woman with curly blond hair that has begun to turn gray speaks to the receptionist, notices us, and casually introduces herself as Dr. Moore. She shakes our hands warmly. I am surprised at how she looks, although I cannot say how I imagined her. She tells us she will be with us in a few minutes, and, in fact, she soon returns to escort us to her office; how different from being led there by a receptionist. She seats us not in front of her

desk but at a round table to which she pulls up a stool for herself. Just like a kitchen table, so we are equals here, though her stool is slightly higher than our chairs. She tells us that she has spoken with Dr. Cody and read my reports. She finds a pad to take down some information, and she puts on the half glasses that hang on a chain around her neck. She inquires about my children and responds to my worry about them by maintaining that children are pretty resilient in these situations. I gratefully take in this first gift from her, these words I will use to calm myself. She inquires about how I am feeling after the mastectomy, acknowledging its significance without making it too big a deal. Because she has asked about me, my emotions run very close to the surface and threaten to erupt at any moment.

David and I begin to assume our roles with her. This time I do most of the talking, though I feel young and a bit inarticulate; he is rather quiet and, even after a relationship of twenty years, this surprises me when it happens. I think of him as big, noisy, and knowledgeable and expect to hear more from him in this meeting. But I am in charge today, perhaps because this is my disease, perhaps because he is sometimes quieter and I more talkative than I generally think. I glance at Dr. Moore's credentials on the wall. She is a graduate of Smith College and Columbia University medical school, so I assume that she is upper class and Protestant. She must be about fifty. But she is at that point in middle age when she could look older or younger at any moment. Her glasses make her look grandmotherly, but she treats me as an equal; she strikes me as being someone with whom I could be friends. I imagine she makes

everyone feel this way. She speaks with the authority of an accomplished professional. I like that she becomes in my mind whomever I need—a peer, a mother, a grandmother, a competent doctor.

She tells us that she would like to review my pathology report with us as a way to sort out the question of chemotherapy. She takes a piece of paper and draws a line down the middle, labeling one side positive and the other negative. In the positive column she writes, first, that the tumor is small, 1.7 centimeters, probably a little smaller in reality, as Dr. Cody said. Second, the cell type is not the best and not the worst. I'm beginning to think of this as a diagnostic category, used by all doctors for my cell type. Dr. Moore lists the cell type under the positive column, though I'm not sure why and I still don't ask. Third, my lymph nodes are all negative. Because the mastectomy removed all of the breast tissue on that side, my situation looks very good. One could make a convincing argument that chemotherapy is not necessary.

On the other hand, she continues, chemotherapy would boost my survival rate by three or four percentage points. Although some women choose not to go through chemo for such a small margin of improvement, others want to gain the increased margin if they can, especially if they have children. This is a discussion about what sort of chances I want to take with my life, and having children makes it simple: I will take no chances. But if I had no children I would be considering how much I would fight for my own life.

Now we turn to the negative side of the equation. It is likely that chemotherapy will cause a premature onset of menopause. Because of my breast cancer, estrogen replacement therapy is probably not an option, she tells me. Great, I think. Finish chemotherapy and move right into menopause without any of the relief from symptoms that estrogen provides. I recall my mother's years of hot flashes, and I know that being of slight build and northern European descent already increases my risk for osteoporosis. If I get through this cancer, I'll be a prematurely hunched over little old lady whose bones break easily. Still, that would be a small price to pay for my life.

I'm particularly worried about the side effects of chemo. I ask Dr. Moore about the long-term effects, and I explain that I have always suspected that radiation caused my hearing loss and possibly this breast cancer as well. She understands my wariness of breast cancer treatments and assures me that follow-up studies of people treated with the drugs I would be given indicate no increased risk of other cancers over a twenty-five-year period. "Could chemotherapy be repeated if I had a recurrence?" I ask. "Yes," she replies, "you could do this protocol again, if necessary." I comment that chemotherapy in my situation seems to imply a belief that breast cancer is a systemic disease; she agrees that this is the premise. I know that this notion will sway me, that I will not rest if I have not treated this potentially systemic disease systemically. It does not escape me, however, that my body may already be free of cancer cells or left with a number small enough to be handled by my

immune system, in which case the chemotherapy would not be necessary. I'll never know.

Dr. Moore presents the question of chemotherapy as being my decision, but she lets me know that she will make a recommendation. She is still waiting for the results of the estrogen-receptor test. Because chemotherapy interferes with estrogen production, it is more likely to be effective if my tumor is estrogen receptive. This test is not generally of great significance, but in my case a little more information might push us one way or the other.

Dr. Moore explains that the chemotherapy routinely used for stage-one breast cancers is CMF, a combination of three drugs—Cytosan, methotrexate, and 5-fluorouracil (5FU). CMF is generally given according to one of two schedules: on the first and eighth day of a four-week cycle or in a slightly higher dosage once every three weeks. Statistically, there seems to be no difference in the outcome of the two regimes, but Dr. Moore is more accustomed to the older, four-week regimen and it would give me slightly more chemo in total. I calculate twelve treatments instead of eight. Terrific.

She explains that many people do very well over a course of six months. They continue to work, perhaps feeling some nausea and tiredness the day or so after a treatment. When I describe the difficult time that I had with nausea and vomiting during my radiation treatments, she promises that she will do everything possible to help me manage. Women generally lose between 40 and 60 percent of their hair, though whether I will need a wig will probably not be clear until the second month or so. It's good to plan ahead for that possibility. She tells me this matter-of-

factly, signaling that this is not something to get too worked up about. I've already developed a public stance on hair loss. I'm going to act maturely, even if I want to scream to the universe, "No, this can't happen."

David, who has been quiet, now asserts that we will do anything that is necessary to improve my chances of survival. Here we go again, I am thinking. Not only will "we" do any treatment imaginable to make me better, but "we" were not intent on saving my breast. How bizarre it must sound to Dr. Moore to hear David discuss "our" going through chemotherapy. I always wondered how Dr. Cody thought "we" could do without the breast. There is a thin line between empathically identifying with my experience and confusing mine with his. Sometimes David crosses the line.

When I had Hodgkin's disease, David developed a lump on his neck that matched my lump exactly in location and size. He worried silently for a long time, not wanting to upset me. "You can't be serious," I responded with a touch of sarcasm. The surgeon was not so cavalier. Because he could not feel a matching lump on the other side, which would have indicated that this was simply a part of David's anatomy, he had to do a biopsy. So we went to the same hospital where I had had my surgery, to the same waiting room, where David saw the same surgeon who had operated on me, on the same day of the week. The surgeon discovered that the lump was, in fact, a muscle. He surmised that David had twisted his neck so many times feeling for a lump that he had actually managed to get his muscle to mimic a tumor. It was quite a remarkable feat, but then again David is suggestible. In his reading he had come

across a little-known case in which the spouse of a Hodgkin's disease patient developed the disease. So why shouldn't he? Before his German exam in graduate school, he nearly convinced his doctor that he had a brain tumor.

Dr. Moore wants to examine my breasts, so she shows me to an examining room off her office. While I undress, I notice on the wall a photograph of a harbor in a place like Cape Cod and a framed citation given to Dr. Moore for her work on the medical ethics committee. I'm glad. It confirms my sense that she is committed to good medical practice. She returns with the slides from my mammogram and views them on the screen before examining me. She comments on the neatness of my scar, and asks which plastic surgeon did the implant. I mention Dr. Breckman and indicate my annoyance with his bedside manner. "He's a good doctor," she says. I probably couldn't find a plastic surgeon I would like better. She examines my right breast and feels nothing of significance. She notices the small scar near my right nipple where Dr. Cody did the biopsy. She's glad to hear that the biopsy showed no signs of cancer. I tell her that I worry about that breast anyway. "This is your second cancer," she says, "Of course you worry."

After the exam we return to her office and she suggests that we think over the question of chemo this week. There's no big rush. I mention my plan to obtain a second opinion. "Of course," she says, "perhaps we should meet after that and pool all our information. It's always good to have more people considering your situation." She's so professional, so confident. By then she'll have the results of the estrogen-receptor test and be ready to make a recommen-



dation. Thank God. Although this is ultimately my decision, I appreciate that she will not leave me completely alone with it.

We stand up, shake hands, and walk with her to the front desk. She tells us about a conference she is attending in Washington to discuss President Clinton's health plan. I manage to converse, but I still feel like a needy little girl, certainly not like a professional woman myself. She asks about my work and suggests that I proceed slowly; women often crash a few weeks after a mastectomy. She's named what's begun to happen to me—crashing. Although I bounced back after the surgery, I've been feeling much more frightened and out of control. I could fall apart right here with this doctor who, like a good mother, articulates the experience that I have not been able to describe. She tells me that her patients who are psychotherapists seem to run on a very tight clock, always checking their watches to make it to their next appointments. They worry more than they need to about their patients, she says. She's got my number again. Patients do well. Children do well. Although not completely convinced, I take her advice as permission to withdraw some of my energy from others and focus more of it on myself.



In my week off, I wrestle with how to discuss my breast cancer with my patients when I return to work next Monday. My mind refuses to grapple with this, and I'm

astounded to find myself feeling more anxious about telling my patients than I did about telling my own children. With Molly and Zach there was no question of whether to tell them; they would have known that something serious was wrong. And won't my patients know? They'll see my wig if I need one. They'll sense my physical state and my feelings. In talking to colleagues, I learn of psychoanalysts so committed to the concept of the analyst's anonymity that they actually go through treatment, wig and all, without telling their patients. Although I know I couldn't pull that off, I sometimes think that I should find a way to keep my crisis to myself, to protect my patients and maintain the illusion that I will never abandon them. I come to the conclusion that telling my patients is the right thing to do and I'll have to live with the fact that I'm not following the rules. I will tell them, except for a teenaged girl who has just begun to see me; she will be at camp for the summer and this information can wait. It seems disrespectful, even damaging, to pretend to my patients that something so threatening and probably obvious is not happening. And we would miss the opportunity to discuss openly their feelings about illness and death, their fears of abandonment.

Most of them are stunned, saddened, frightened for me. Some tell me that they are relieved to know the nature of my surgery, that they had guessed breast cancer or imagined a worse cancer. They had been worried about me during my time away from work and were grateful to receive my call telling them that the surgery went well and that I'd see them as planned. They had struggled with how to communicate their concern, whether to send a card or flowers

or a gift. Some did, some didn't. Many tell me how appreciative they are of my sharing this personal information. What if I had not told them and then something happened to me? They would have felt betrayed and resentful about never having had an opportunity to say goodbye.

After our initial sessions I relax and can hear more about their fears of loss and death, their anger that this has happened. Many worry about how they will talk to me about their problems if I have chemo; they won't want to impose on me. Others fear that I will be distracted and unavailable. I say that I will continue sessions, as I hope to, only if I feel I can do my work. Some of my female patients whose mothers had breast cancer tell me that they expect to get the disease themselves and are not surprised about me. They describe their mothers' illnesses and scars but often avoid their most painful feelings. Not everyone. One woman misses work and cries for days, less for me than for her mother after whose death she could not shed a tear. I am quite astounded at the high number of my patients who lost a parent at an early age. I hope they do not lose me, and I hope my children will be spared the trauma that has so affected these patients' lives.

By my third visit to Dr. Breckman I know the routine. At his office on Fifth Avenue the receptionist buzzes me in and I push hard to open the heavy, metal door. While I wait, I read slick, expensive magazines or I watch the other patients and try to determine the nature of their problems. I am usually called by one particular nurse, who listens well and answers my questions much more completely than the doctor. She offers good advice: to prevent a yeast

infection while on antibiotics, take acidophilus tablets or try a course of Gyne-Lotrimin; to fill out your bra until the expander is fully inflated, use a shoulder pad. We talk about her upcoming wedding as she gets things ready for my procedure.

Dr. Breckman comes in and checks on the amount of saline he has previously injected. He tells sexist jokes about nurses while he searches for the valve that he placed under my skin during surgery, and then inserts the needle. I feel the pressure as more saline fills the expander. It's strange to have a different-sized breast every week. He asks if it hurts and coaxes me to let him insert a little more. He doesn't push hard, assuring me that he can complete the inflation in ten or twelve visits. It's up to me. I have him stop at fifty-five cubic centimeters. He then asks if I had pain after the last injection, and I report only discomfort that day; I never need more than a Tylenol. I make an appointment for the next week.



I'm still agonizing over the question of chemotherapy. David really leaves this one to me. I can't stand the thought of these treatments, but how can I forego a chance to kill off some more cancer cells if they are there? Nevertheless, I fear taking such powerful chemicals when at best they will improve my chances of survival only slightly. Even though I've been assured otherwise, I worry that they may cause permanent damage. I want all this to be over with. Why

can't surgery be enough? Why must I endure six months of treatments, sickness, and humiliation? But how can I not do this for the sake of Molly and Zach? And I need insurance against feeling responsible should I have a recurrence.

On Tuesday David and I have dinner with friends and I share with them my dilemma about whether to have chemo. The woman in the couple would not. She has seen friends go through these treatments and she could not stand it. Why is she telling me this? Would she not go through chemotherapy herself for her two sons? Her husband keeps repeating that we should follow my doctors' advice because doctors know best. He ignores that mine is a borderline situation and that the doctors are not claiming to know what's best.

David talks later about how he always thought, perhaps naively, that the real task with serious illness was to find a good physician. I have good doctors, but I still need to become educated and make decisions. It seems doubly unfair. Isn't suffering from cancer enough? Why must I simultaneously make the most difficult decisions of my life?

On Wednesday I receive in the mail from a friend a book, published by Wedgestone Press, titled *One Answer to Cancer: An Ecological Approach to the Successful Treatment of Malignancy* by William Donald Kelley, D.D.S., M.S. A dentist? I browse through the testimonials from people with incurable cancers who claim to have been cured by this approach. I begin to wonder why I have chosen such a noxious treatment as chemotherapy; perhaps a change in diet or some nutritional supplements could cure me. I turn

to Kelley's introduction and read his story. After various treatments for muscle aches, pains in his chest, and depression, his frustrated physician sat him down and told him there was nothing wrong with him; it was only in his mind. After some time Kelley returned to this physician with further complaints. His doctor prescribed more tests and found nothing but sent him to a specialist who suggested a biopsy of the pancreas. This suggestion shocked Kelley and convinced him that he had cancer, though he does not mention whether he ever had the biopsy. He did, however, give himself a biochemical test for the early detection of cancer—a test that doctors have found unreliable and have stopped using because it detects cancer when no other clinical signs are present. For Kelley this simply meant that the test identified cancer early, before any tumor appeared. He gave the test to his wife, his mother, and his three children, all of whom, except one child, turned out to have cancer according to this test.

In retrospect Kelley believes he failed to heed the early warning signs of cancer—gas, weakness of the eyes, tiredness, muscle weakness, changes in hair texture or color, hernias, and depression (as characterized by loss of interest in one's work). Funny, everyone I know has some of these early warning signs. Cancer, Kelley explains, simply indicates an active pancreatic enzyme deficiency, and his book purports to explain this deficiency scientifically, though it leaves me longing for some peer-reviewed and controlled studies. Cancer can generally be cured by using enemas to detoxify the body, taking nutritional and vitamin supplements now available in New York from Dr. Nicholas Gonzalez, who has carried on Kelley's work, and maintain-

ing a proper spiritual attitude. Not everyone has a proper attitude, he points out. So not everyone will be cured? I think I'll stick to chemo.



If I do have chemotherapy, I already know that I want to work with Dr. Moore. But getting a second opinion is the responsible thing to do, or at least it is what everyone expects me to do. In New York that means an appointment at Sloan-Kettering's Breast Center. Dr. Larry Norton, the director, seems to be highly respected but is too busy to take new patients. It's Thursday and I have an appointment instead with his associate, Dr. Klauber. David accompanies me. The Breast Center, hidden away on East Sixty-fourth Street, is well endowed and provides a wide spectrum of services for women who have breast cancer. Its interior decorating is reportedly state of the art. I arrive for the appointment and am moved along from desk to desk to fill out forms and supply insurance information. A large waiting area with plush carpets and comfortable couches and chairs, all in muted colors, is warmly lit. No glaring fluorescent lights here. And the staff is very pleasant. This is the place to be. So why do I feel as if I'm on a conveyor belt?

There are many women in the waiting room, all of them under fifty, and of normal weight. They shouldn't have breast cancer, according to the conventional wisdom that says older or overweight women are the ones at risk. It also says that a woman is more at risk if breast cancer runs

in her family, but in fact only a very small percentage of women with breast cancer have a family history of the disease. The women talk casually with one another and would certainly include me in their conversation. But do I want to talk? I am a newcomer to this world, and this is an initiation I'd rather avoid. An attractive, dark-haired woman in her forties who observes me waiting anxiously engages me in conversation, telling me about her first two rounds of chemotherapy. She feels tired but she is working. After her last treatment she managed a six-hour car ride to visit friends in Syracuse. Her hair is thinning but still looks fine. She assumes I'll be having chemo and tells me to drink plenty of fluids. She indicates a room with a small refrigerator full of drinks where I can get some juice. I then meet a forty-five-year-old woman whose tumor was five centimeters wide when discovered by mammography. She's wearing a great wig. She takes two days off after chemotherapy treatments but could even work those days, she claims. The third woman I meet, the mother of a three year old, had not had a mammogram. If she had, her breast cancer could probably have been discovered earlier; it is now in her bones and in an advanced stage. Why is there even a question about mammograms for women in their forties?

On the way to Dr. Cody's office last week I bought the May/June 1993 issue of *Ms.*, in which all of the articles are about breast cancer. Like the *Times*, *Ms.* reports on studies that indicate no statistical increase in rates of survival among women in their forties who have mammograms. *Ms.* also discusses the conflicting opinions on the value of mammograms. But I'm not satisfied. However balanced



the reporting, all I want is a long article expressing outrage at the undervaluing of mamograms, pointing out that many women in their forties have had tumors that were detected early. I already know ten women in this situation. Perhaps this fact is not statistically significant, but I can guarantee that it is personally significant to these women, and I worry that the real underlying pressure against mammograms is that they, and biopsies, are costly.

This issue of *Ms.* also highlights the angry, political response of many women to breast cancer. Some women choose not to wear a wig and to appear bald in public as a statement that breast cancer is a reality not to be hidden. Others decide against breast reconstruction after a mastectomy and let themselves be seen with one breast. I consider myself a feminist who believes in political action. So why am I put off by this public movement? I doubt that I could proudly show my scars or my bald head. I feel sad, not proud. I'm trying to mourn my losses and accept the damage that has been done to my body. I need to do this in private, and wigs and reconstruction may afford some privacy.

As I sit in the Breast Center and talk to these women, I find myself admiring how well they have hidden what they are going through. I realize that this is what I aspire to—looking as if everything is fine. But maybe this effort to appear to be fine, to wear wigs and breast prostheses, does in fact contribute to the invisibility of breast cancer. Maybe we should be showing the world, by refusing to cover up our disease, how numerous we are and how many more resources are needed to do something about this disease.

The next woman I meet is angry—angry at her doctor, at the Breast Center, and at her brother, a physician, who insists that she come here, the “best place,” even though she has her own doctor, whom she trusts, at another reputable hospital. She tells us tales of long waits and of doctors not returning calls as she struggles to decide whether to have chemo, knowing it will probably make her infertile.

David and I wait for three hours to see Dr. Klauber, and, because we’ll be so late, we call and make arrangements with Eve, our babysitter, for the children to be dressed and taken to Zach’s spring orchestra concert. I’m furious. Never has a doctor kept me waiting this long. Finally, we meet Dr. Klauber, a rather overweight, taciturn man who makes no apology for the delay. He takes my history, tries to impress us with his knowledge, and talks patronizingly of Dr. Moore, though she is clearly more experienced than he. Given the arrogance of the medical profession, how did I ever find Dr. Cody and Dr. Moore? In the course of the physical exam, Dr. Klauber learns from me that I took birth control pills for a short time, and he nods knowingly, as if he’s identified the cause of this cancer. I wonder why, if he knows about this suspected link, he hasn’t hired a public relations firm? Besides, I know that the studies linking birth control pills and cancer are inconclusive at this point, and that much depends upon a woman’s age when she took the pill, the length of time she was on it, and the dosage and combination of hormones.

I return to Dr. Klauber’s office and he then disappears. I talk with David, who totally dislikes him. Ten minutes later, Dr. Klauber returns. He remains standing, as if he has an important announcement to make. He tells us that

he has just met with a colleague and they agree that, of course, I should have chemotherapy; anyone with a tumor larger than one centimeter should.

There's something else he must tell me, he adds, with what strikes me as a gloating demeanor. "Because of your history of Hodgkin's disease," he says, "we would highly recommend a second mastectomy before you begin further treatment." I am stunned. I look at David for his reaction but cannot read him. "Why?" I ask. "Well, there really are no studies of the incidence of breast cancer among Hodgkin's disease survivors, but we saw one woman last week who developed a cancer in one breast and had a pre-cancerous condition in the other." I point out that when my right breast was biopsied the tissue was clean, as was my mammogram and my physical exam. "Yes," he replies, "but the cancer could be hiding in some part of the breast that was not biopsied." So we should cut off my breast because I might someday develop cancer? Perhaps everyone with even a slight risk qualifies for a mastectomy.

I try to remain calm and sound rational, though my emotional barometer registers shock. This suggestion leaves me feeling panicked, as if my prognosis is worse than I thought. Why else would these doctors feel that my first-stage breast cancer needs to be clobbered, and I with it? Nothing seems enough: not a mastectomy, not chemotherapy, and probably not a second mastectomy. Why is this doctor alarming me so? And why did the other doctors reassure me?

I ask Dr. Klauber to give me again the rationale for a second mastectomy. Well, you had radiation in both breasts. If you got cancer in one, you might get cancer in the other.

Yes, but I had much more radiation at the site of the tumor, nearer my left breast than my right. I lose track of my thinking. My mind races from one thought to another. This is Sloan-Kettering. If they say I need another mastectomy, how can I not follow their recommendation? Haven't I been secretly tortured by this question? Then again, Sloan-Kettering is known for recommending the most radical treatments, sometimes more radical than necessary. But they may have reason, given the number of women they see die of breast cancer. And Dr. Klauber did say they are glad that we Hodgkin's patients have been kept alive this long. Why lose us now? I begin to have a curious feeling of relief. Dr. Klauber is reminding me that I could get cancer again. He's offering me a recommendation that fits with my old, magical solution of cutting off offending and potentially offending body parts. Perhaps it is a good idea. I think about my patients. How can I take off again for an operation? If I need to I will. Dr. Klauber tries to reach Dr. Cody, but he's gone home for the day. I'll call him tomorrow to set up a date for surgery next week.

We rush uptown to Zach's orchestra concert and arrive at intermission. Our friends David and Zina, who have come to hear their daughter perform, see on my face the traces of my anxiety and fear. In their warm embrace I begin to cry, shaking as my effort to hold my desperation inside fails. Molly sees me crying and her face crumbles as she runs over to me. I sense her fragility immediately, and I rally, desperately, to save her from seeing more of my raw pain, much as any mother rallies when she sees her child in danger. I hold her in my arms, and she asks what's wrong. I tell her that I'm very upset about the medicine I will have

to take because it will make me feel sick for a couple of months, but I'll be fine. With my arm around her I stroke her hair until she relaxes enough to go off with her friends, but I can't stop thinking about her terrified little face.

Because I'm tied up the next morning with patients, David calls Dr. Cody to make plans for surgery. Dr. Cody is astounded by Sloan-Kettering's recommendation and makes it clear that he strongly disagrees. Despite my dislike of Dr. Klauber, I had accepted his advice concerning what I must do, numbly acceded to the next terrible trial, relieved to be rid of all breasts. I spent last evening adjusting to the idea of another surgery, convincing myself that I manage surgery well and bounce back quickly. Dr. Cody's disagreement is another blow. Now what do I do? Two opposing medical opinions seem worse than a mastectomy; they mean that I will have to make a decision, not simply follow orders. Dr. Cody realizes that David and I are very upset and suggests that we drop by his office the next afternoon before my appointment with Dr. Moore. When we see him, he's angry enough to let us know his feelings about the situation. He thinks the doctors at the Breast Center are under enormous pressure to make quick diagnoses. Dr. Cody simply cannot find any basis for their recommendation other than one anecdotal case. He repeats that the mammogram of my other breast showed nothing; that my breast exam indicated no problems; and that the biopsy of tissue from my right breast showed no cancerous or precancerous cells. Of course he will watch that breast, but with no indication of a problem he cannot justify a mastectomy.

In addition, it does not make sense to delay the beginning of my chemotherapy, and another mastectomy right

now would do that. We know that I had a cancer in my left breast and it's important to begin the chemotherapy, which we all are now in agreement about. In a way the discussion of a second mastectomy, because it seems such an extreme recommendation, leaves me feeling as if chemo is the least I can do in the way of further treatment.

I try to explain that, all this aside, I am now left with an impossible decision. If I decide not to have the second mastectomy, I will continue to worry. If I go ahead with it, I face another surgery with the ever present possibility of complications, with weeks of recovery and decisions about another implant, and with a delay in beginning chemo, all for possibly no reason. Dr. Cody understands my dilemma. The fact that I've had cancer in one breast increases the odds slightly of a tumor developing in the other breast; he will be checking my other breast closely through regular exams and mammograms. Any problem will likely be found early. If at a later date it seems appropriate or if I find that I cannot live with the worry, I may then decide to have a second mastectomy.

I feel at a loss. I trust Dr. Cody and know that I will go along with his recommendation, but now I have this albatross of anxiety around my neck. How will I get rid of the worry? I even wonder how I might persuade Dr. Cody to do a second mastectomy. I would probably cut off my arms and legs if someone suggested it, and Sloan-Kettering's recommendation seems headed in that direction. Finally I decide against another mastectomy; I will go along with Dr. Cody's recommendation only if he agrees to watch me like a hawk so that any sign of cancer can be detected early.

We meet with Dr. Moore at half past four. Today I am not soothed by her voice. Even more than I, David needs to vent his outrage about Sloan-Kettering. Dr. Moore listens sympathetically but doesn't join in his anger. She agrees with Dr. Cody that there is no reason to assume a problem in the second breast. The doctors at Sloan-Kettering are very good doctors. She knows Dr. Klauber; he's worked in her office and he is very bright. I wonder why she doesn't comment on his bedside manner. She spoke to him after my call earlier today, and he said that he was only suggesting that we consider a second mastectomy, clearly backing away from the statement I saw him write in my file: "We strongly recommend a second mastectomy."

I quickly add that Sloan-Kettering's opinion that I should proceed with chemotherapy did help me in reaching a decision to do so. She agrees with my decision and informs me that the results of my estrogen-receptor test are positive, a good sign for the effectiveness of the treatment. She suggests that I begin next week. We settle on the first two Fridays of each four-week cycle as the day for the treatments so that I can recover on the weekend before work on Monday. I should set up an appointment with Marta, the nurse who will work with me. She likes to spend some time with patients in advance to discuss the effects of the medications and ways of coping with them.

In the evening, David and I work out a plan for the kids during my chemo treatments. Dinner will be simple or we'll order take-out meals. I will try to be with them at dinner and in the early evening to help with their homework and music practice. When I need to go to bed, David

will take over and put them to bed. I tell him that I fear that this treatment will wear us down completely. With appointments, naps, nausea, and early bedtime, I am going to be far less available. David will be assuming the endless errands that I usually do, taking over even more of the care of the children. He is going to get tired out himself. We decide to ask Eve for some help.

Eve agrees to come on Thursdays to spend a few hours with Molly—playing games, drawing, and helping her with homework. Molly loves Eve, and she can certainly use the additional attention, given that David and I are so distracted. At sixteen, Eve is becoming a lovely young woman. Her generosity is wonderful, but I'm also aware that we are bringing her into this world of ours that includes cancer. She will see how the chemo affects me—whether I lose my hair, gain weight, or look gaunt. How could it not frighten her? As the oldest child in my family, I sometimes felt that I knew too much. When my mother had a miscarriage, I helped out, but I was frightened and alone with what I imagined was happening to her, with my feelings of loss about the baby, and with my inflated sense that I had to be responsible for my siblings. I'm concerned that Eve will worry and feel too responsible. Her mother assures me that she will take care of talking with Eve.

I resent the amount of time and energy that coping with the effects of chemo will take. I love to go to the country, to have the house full of friends, sharing meals and conversations while the kids run in and out, but I doubt that I'll have the stamina. I had looked forward to conversations with my two sisters who are pregnant, but now I will barely manage to keep track of their development.



Many times in the past few years I have said to David, “Thank God no one close to me is sick or dying; I don’t have time to care for anyone.” Now I am the one who is sick. I have no time for an illness that so aggressively forces itself to center stage, demanding all my attention and pushing my family and friends out of the way.



It is a sunny, spring day, two weeks since my mastectomy, and I feel stronger and healthier. Our friends David and Dinitia are preparing for the bar mitzvah of their twin sons on Saturday. We learned this week that they plan to seat us at lunch with people we might find interesting—David with some science editors and me with some literary people. I find myself panicking at the thought of even one meal with people I do not know. How can I make small talk when all I can think of is cancer? How will I keep from losing my grip on the rules of social etiquette, from telling these strangers the intimate details of my mastectomy? I will feel exposed and they uncomfortable. I call Dinitia who arranges for us to sit with close friends.

The ceremony is very long and in Hebrew. The boys do their readings and maturely present their commentaries. I focus on a point implicit in their talks: that their coming of age has meant embracing Judaism and consequently rejecting Christianity. I am disturbed that they, in adopting the religion of their father, reject the background of their mother. Dinitia herself is not bothered by this; she doesn’t identify strongly with her parents’ tradition and

shares the Judaic values of her husband. I realize that I am upset not by the twins' rejection of their mother's heritage but by the possibility that my children will overlook me, that they'll identify only with their father. I am afraid I will die and be forgotten by them.

After the service we walk up West End Avenue toward the restaurant on 107th Street, behind all the children, who are exuberant about shedding their good behavior. I chat with Marsha and Richard on the way. Marsha has been solicitous and supportive, calling with the names of friends I might contact who have had breast cancer. Richard listens to me with understanding. He tells me how worried they were when Marsha had a biopsy. At our table I join Pam and Roger, whom I have not seen since they visited me in the hospital. Roger inquires jokingly about my mental health, but I appreciate the seriousness of his question.

I am grateful to these men for not being afraid to talk to me about my breast cancer. A number of my close male friends have let their wives speak to me for them. Some haven't mentioned my cancer even when they see me face to face. I suppose they are imagining my breast that isn't there, conjuring up the empty space, as I did when I visited Jan after her mastectomy. I'm angry and hurt that these men do not find a way to acknowledge my pain, but at least they don't literally flee. Last week an acquaintance with cancer told me about running into a friend on the street. The friend immediately ran away from her, toward a cab, while shouting, "I haven't called you because I just can't handle it."

Seated at my table is a science editor at the *New York Times*. We talk about our children and then about her

work. I soon launch into an emotional critique of the reporting by the *Times* on the studies that suggest no increased benefit to women in their forties from mammography screening. Why didn't the *Times* give greater emphasis to the arguments of those who still favor testing women in their forties? I try to sound rational but am vaguely aware that I may lose my grip. Nevertheless, sensing that she is sympathetic to my point of view, I pick up steam. I tell her about all the women I have met whose cancers were diagnosed through a mammogram. I go on and on, vaguely aware that my behavior is inappropriate. This is not a polite topic for a bar mitzvah lunch. But I've cornered this woman and won't let her go, even if she had nothing to do with the article. She kindly listens. I like her and wish I could allow us room to get to know each other.



It is Tuesday, May 18, and I am meeting with Marta to discuss the details of chemotherapy. Marta is Panamanian and very beautiful. She carries herself with consummate dignity and radiates warmth and intelligence. She has a young daughter whom she clearly adores. Marta explains that, as a team, she, Dr. Moore, and the other nurses will do everything they can to help me through these treatments. She views chemotherapy in a positive light, as a very powerful weapon against cancer. She explains that the drugs used in chemotherapy interfere with the process of cell division in cancer cells, causing the cells to die. Because different drugs interrupt this process at different points, she

tells me, I will be given more than one kind of drug. Chemo acts on all rapidly dividing cells—bone marrow cells as well as cancer cells—so they space out the treatments in order to give the bone marrow time to recover. The goal is to decrease cancer cells in the body to a number that the immune system can handle.

The three drugs referred to as CMF will be given in different steps. Methotrexate and 5-fluorouracil (5FU) will be given intravenously on each of the first two Fridays of the cycle; during those two weeks I will take the Cytoxan in pill form three times a day. Then for two weeks I will have no treatment so that my body can recover. My blood cell counts will be taken before each treatment and again about ten days after the second one. The white cell counts are important in regulating the chemo. On the twelfth day of the cycle, I will be most susceptible to infection and should avoid contact with large crowds or people who are sick. If my counts have not come back up by the next treatment, it can be delayed a day or two without compromising its effectiveness. Marta shows me a diagram of the one-month cycle that she is describing.

The major side effect is nausea. Fortunately, there are some new, more effective drugs for counteracting it. The team will work with me to adjust the type and dosage of anti-nausea medication to help me manage. Generally, people have some reaction to the chemo for a day or two after each treatment, but I may be able to function normally most of the time. I tell Marta, as I tell everyone, how little relief I had from the nausea related to my radiation treatments for Hodgkin's disease, but I do feel encouraged by

her optimism. I realize now, sitting here, how little attention the radiologists in Boston paid to helping me manage the side effects.

Marta suggests that I stock up on bland foods such as bagels and potatoes and that I avoid spicy foods. Because I may be tired, I should rest and let others help me out as much as possible. She adds, quite to the point, that I must focus on getting better for my children, even if it means being less available to them in the short run.

She tells me that some people find it helpful to listen to music or a meditation tape while the chemo is being administered. She suggests that I imagine the chemicals attacking the cancer cells, that I cooperate with rather than fight the chemo. I can predict that I'll fail at this task. I'm the kind of person who registers every irritation, who is bothered by someone smoking at the opposite end of a room, by noise in the background, by lettuce that is brown at the edges. It's hard to imagine not loathing every minute it takes these chemicals to enter my body. Besides, I'm skeptical about the efficacy of a positive attitude. Why not be honest about one's misery? Yet Marta is beautiful and encouraging; she makes me want to try.

According to Marta, some people experience an odd, metallic taste in their mouths from the chemo. Sucking on Lifesavers or hard candy usually helps. Some develop mouth sores; if I do, I should call the office right away. Because my hair is likely to become very dry, I might consider using conditioner. I will probably lose hair, and I may need to wear a wig or scarves and turbans. Marta gives me a list of places that sell wigs, including a shop run by two

women who themselves had breast cancer. They also sell underwear, lingerie, and scarves. She encourages me to call her anytime; she is here to help me.

During the week we talk to Zach and Molly about chemo. I tell them again that the doctor thinks he removed all the cancer cells when he took out the tumor. I still am not specific about the mastectomy. I tell them I'm probably better already, but my doctors want to be sure by giving me some medicine that will kill any cancer cells that may remain. Because the medication has to be very strong to kill the cancer cells, it might also make me sick. "No, it's not strong enough to kill me, just strong enough to make me feel sick and maybe vomit sometimes. It will get the bad cells, but it won't get me." "Like roach killer, Mommy?" "Yes, my little New York daughter; it kills bugs but not people."

I tell them that Daddy will be doing many of the tasks we usually share—shopping, making dinner, and putting them to bed—and that I will have to take the medicine for six months, which will seem like a very long time. "But after a while you'll be all right?" asks Zach. "Yes, Zach I'll be all right." I'm beginning to see that he copes by taking the long view—that eventually I'll be better. I hope I can take that view. I assure them that, when the treatment has ended, life will return to normal.

I spend the week preparing myself by resting, taking walks, and speaking on the phone to friends about my fears. Time for everyone's anxiety again. One friend heard that tamoxifen is a drug that cures cancer and I might want to take that instead of having chemo. Another tells me that her cousin underwent an alternative treatment years ago

when he had a terminal cancer diagnosis. He's now fine. "It's a shame that this method, a proven alternative to chemo, has received so little funding," she says. It's a shame that you are so insensitive, I think. Why are so many people talking about the efficacy of every treatment except the one that I am having? They must be terrified themselves of this chemotherapy, with its bad reputation. Not everyone ignores what I am feeling; many listen to my fears and withhold their own. They ask what they can do. I remember Marta's advice about accepting help. Promises of chicken, soup, and casseroles roll in.

An old friend, Michael, is passing through New York and stops by to visit with David and me. I feel anxious in talking with him because I fear that he will judge me. He's had some success with homeopathic cures and has already spoken with David on the phone about vitamin treatments for cancer. I have spent the past few weeks learning the language of breast cancer treatments—lumpectomy, radical and modified radical mastectomy, reconstruction, breast implant and reduction, chemotherapy, Cytoxan, methotrexate, and 5FU. I have come to think of my body in very concrete terms and the cancer as a determined killer out to destroy my cells. I have been steeped in the medical world's vision of attacking the cancer, of killing it before it kills me.

I have also struggled endlessly with my fears of chemotherapy. It is toxic, a poison, a killer. That is the point. I hope it will kill the cancer before it kills me. But I'm very frightened. For years I've been careful about what I eat. I avoid red meat and routinely eat fresh fruits and vegetables. I don't smoke or use drugs and I drink little

alcohol. And now I am choosing to have toxic chemicals injected into my veins. I will be reminded of this toxicity every day. My hair will fall out. I will feel tired and nauseated, and I'll have a metallic taste in my mouth. I will know every minute that these chemicals are inside me, killing off parts of me—the cancer parts, I hope, and not just the other parts. Having lived through radiation treatments, I know the horror of losing my hair, vomiting, and feeling desolate.

I let Michael know my fears, hoping he will sense my conflicting emotions about chemotherapy and not add to the struggle. But sharing my vulnerability seems to have the opposite effect. He assumes that I'm open to suggestion and urges me to try vitamin therapy instead. I feel enraged and become very quiet. How do I respond to this? Is he saying that I'm foolish for choosing Western medicine when there is a cleaner, more benign cure? Would he really refuse chemotherapy treatment if faced with the decision? Didn't he go to the most reputable specialist in New York when he had medical problems? Does he truly believe that the entire medical establishment, in its arrogance, refuses to look at this "proof" of the curative properties of vitamins?

David responds calmly and says that he would be interested in seeing the studies. I know that my silence communicates annoyance, and I am critical of myself for not having found a way to be gracious and disengaged in these situations. Were I comfortable with my own decision, I would probably react less defensively. But how do I defend this grotesque decision of mine? I talk to David later about how hurt and angry I am. David is not in conflict. He feels that there is no solid, scientific evidence that these alternatives



cure cancer. He reflects on the irony that he, a historian of medicine who is generally critical of the medical establishment, avidly supports medical intervention for me. He would have supported my decision for or against chemotherapy, but I know he's relieved that I have chosen this route, and his support keeps me on track.