TOUGH ASSIGNMENT

When her doctor diagnosed breast cancer, this veteran reporter stumbled into the story of her life.

The image that recurs is of a young artist in a university program, sculpting a life-size clay figure. The sculpture is nearly complete. He studies it again, then takes a piece of wire, holds it taut by wrapping it around the knuckles of both hands and slices off the right breast. He smoothes the surface of the chest where the breast had been and swathes the work in silky wet rags so the clay will stay moist for the next day. Only he never returns. In this scene, I am the gray lady in wet rags.

My breast was removed because a lumpectomy and radiation failed to eradicate cancer in it, and the cancer recurred. This happens in about 12 percent of all cases. That seems like very few. Until you end up in the 12 percent.

An imperfect mix of scientific inquiry is the basis for all breast cancer treatment in this era, and the decisions a woman makes about whether to lose or keep her breast inevitably involve an abyss of uncertainty. That is why no one facing the decision to have a lumpectomy or a mastectomy is excused from learning everything there is to know before she makes a decision that will profoundly affect her life.

The First Lady was faced with these unhappy choices recently. No one, except Nancy Reagan, can say for certain what went through her mind before she made the decision to have her breast removed. But it amazed me to learn that though most of her mail honored her courage, she received a number of letters criticizing her choice. How could anyone be criticized in such a situation?

Living with one breast is difficult, a reality I spent a long time denying. The idea of breast reconstruction put me off, though three years after my mastectomy I underwent the procedure. Until then, even when the urge for symmetry would overwhelm me, my impulse was to want my left breast to disappear so that side of my chest would match the blank space with the thin diagonal scar on the right. It disturbed me that my mind leapt to thoughts of disfigurement before I pondered the more logical course of having the breast rebuilt. But I wanted no more anesthetics or knives. And I harbored an irrational fear of what sinister presence the surgeons might find lurking beneath my highly irradiated skin.

Even mastectomy patients have recurrences of the cancer. Again, not very often. But when they do, it is usually a sign that the disease has spread beyond the breast and will mean a countdown to the end.

I am not obsessed with my condition nor my mortality, though it is difficult not to be reminded of both every time I pass a mirror. Still, I am bemused by the steady run of articles in lay magazines that would have you believe no woman need surrender her breast to cancer anymore. I SAID "NO" TO MY DOCTORS trumpeted one story. GOOD NEWS FOR WOMEN! NO MORE MASTECTOMIES! another shrieked.

BY BROOKE KROEGER

EFFORTS

at breast conservation surgery would have been, in my case, a waste of catgut and anesthetics. All of my tissue was diseased.

Such stories create the impression that concern about breast cancer has become exclusively cosmetic—a disease that kills 41,000 American women a year. Another 130,000 a year are diagnosed as having it. One in ten American women, at some time in her life, will be told she has breast cancer. A third of those diagnosed will eventually die from it. In some cases, when the cancer is detected early, the survival rate five years after diagnosis is 90 percent and higher. In others, when the disease appears in lymph nodes, it is 67 percent and lower. When the disease has spread to other organs of the body, there is no ultimate cure.

At press time, National Cancer Institute figures showed a sharp 7 percent jump in the breast cancer death rate for young and middle-aged white women, after more than a decade of steady decline. It could be a statistical fluke; it could reflect the change in treatment regimens. No one knows for sure.

I have been cautioned not to generalize based on my personal experience. The vast majority of women diagnosed with early breast cancer don't have recurrences. What I have experienced is not the norm, nor is the manner in which I have responded to it, nor is the course of treatment I received. That is not to say that my experience is invalid but that every case is unique—and in that alone they are all the same. This is a very important point.

I was diagnosed with breast cancer in October 1982 at the age of thirty-two. Statistically this put me in the "under thirty-five" group, the one with the fewest members but with the highest recurrence rate and the lowest chance of staying alive. My tumor was tiny, well under two centimeters, which classified it as "Stage I" cancer. The importance of early diagnosis cannot be overemphasized. There was no indication of disease in my lymph nodes—a sign that the cancer probably had not taken root in other parts of my body. Several top specialists were consulted. All the risks and possibilities were explained by the surgeon who treated me in my hometown of Kansas City, Missouri. I chose lumpectomy, removal of the tumor and a wedge of normal tissue around it, leaving the breast relatively intact. The surgery ordinarily is coupled with a series of radiation treatments that, at least one major 1985 study has indicated, can be as effective as mastectomy. In the most worrisome cases, where cancer is feared to be growing in other parts of the body or has the potential to grow, chemotherapy is also advised.

My "cosmetic result" was excellent. The only evidence was a thin scar buried in my armpit. But keeping the breast was not my primary motivation for having a lumpectomy. I wanted the quickest possible recovery time, and lumpectomy seemed to offer it. I was the bureau chief for United Press International in Tel Aviv at the time, and the Israelis had invaded Lebanon four months earlier. I was determined to miss the fewest possible workdays, since war in Lebanon was a lot more compelling to me than breast cancer. A postoperative plan was devised and executed at Hadassah Hospital in Jerusalem. Doctors predicted that at the end of the treatment I would have a 90 percent chance of remaining disease-free. The program involved six weeks of utterly painless cobalt treatment that, even with the hour's travel back and forth to Tel Aviv, allowed me to get to work by 9:00 A.M. There was also a gruesome iridium implant that involved threading thirteen polyurethane straws through the cancerous breast, then yanking them out two days later without benefit of painkillers. That was when I first understood the term *seeing stars*. Each tube contained a measured amount of iridium, a highly radioactive substance. I recall this procedure as forty-eight hours of leperhood. No one, least of all a nurse, wants to enter a room where a breast is getting nuked.

Then came a six-month course of chemotherapy, the nausea that does not relent. Chemotherapy is designed to attack micrometastatic disease that may be brewing elsewhere in the body. If there is no evidence of "micromets," the chemotherapy could be highly toxic, side-effect-ridden overkill. Or it could be keeping a more ferocious disease at bay.

Two years after diagnosis is the first milestone for a breast cancer patient. Two years without a recurrence gives hope there could be five, and five is as close to an all-clear as a cancer patient gets. For me, two years later in New York, three months into a new marriage and a new job, the cancer recurred in the same breast, not near the original tumor site, practically under the armpit, but more on the surface of the breast above and to the right of the nipple. Maybe it was a brand-new disease. Maybe the first treatment had failed. No one can say for certain. The decision at Memorial Sloan-Kettering Cancer Center was to classify it as a new primary tumor.

This time I chose simple mastectomy, though for women intent on keeping their breast, some surgeons will go as far as trying to do one or even two more wedge excisions in an effort to obtain a margin of cancer-free tissue on either side of the affected area. Not that I would have considered such a course. But as it happens, doing so would have been a waste of catgut and anesthetics. All of the tissue samples removed from the breast were diseased.

Again, there was nothing in the lymph nodes—good news—but two things were troublesome about the removed tissue: *extensive intraductal carcinoma in situ*, a precancerous condition in the breast ducts, and *lymphatic invasion*, wherein the tumor locally invades the lymphatic vessels. The latter can suggest a more aggressive disease.

So two weeks after surgery I began a six-month course of a more brutal chemo-cocktail, the high point of which was watching my hair gently disengage from my scalp and end up on my shoulders and notepad in the courtroom of then–U.S. District Judge Abraham Sofaer. I am not the first to remark that losing hair is more devastating than losing a breast, even though hair grows back.

At the time, a twelve-member jury was deliberating the outcome of *Ariel Sharon v. Time Inc.*, which I covered for *Newsday*. My sick days from the surgery through the last injection of the dreaded adriamycin totaled six or seven. I coped very well. But I would be hard pressed to agree to go through chemotherapy again.

My interest in the subject of failed lumpectomies—or "local recurrence," in medical parlance—should, then, be obvious. The specialists are very interested in it, too, and made it the subject of an international conference last June. "We're in a time of transition," said Samuel Hellman, physician-in-chief at Memorial Sloan-Kettering and prime initiator of breast conservation in this country. "And when you're in a time of transition, you don't know all the answers."

In Boston, where Hellman started and where the vanguard of the conserve-the-breast movement remains, two-thirds of breast cancer patients now undergo lumpectomies, probably the most in the country. At a weekly conference at Beth Israel Hospital, thirty cancer specialists gathered in a white-linoleum-tiled room to view a series of pink and purple slides of cancerous breast tissue flashed on a screen. The doctor presenting each case would reel off the particulars so his or her colleagues could ask questions and proffer opinions. "Age forty-five, premenopausal, her mother had a mastectomy at thirty-seven and is alive at eighty-one; there are microcalcifications but nothing palpable." "Age forty-eight, small breasts, skin involvement, one palpable node, work-ups all negative." The key underlying question was not "What should be done?" but "Can this breast be saved?"

"It's nice to just do a lumpectomy, but in which patients is that ineffective?" said Jay R. Harris, who led the meeting and is Harvard Medical School's associate director of radiotherapy. "There has to be a happy balance, and the primary focus should be on survival."

This, then, is the wave of the present, determining the minimum amount of treatment a woman with breast cancer can undergo and still get control of her disease. Two years ago, doctors, based on the wide experience of the four Boston hospitals, found that women with the precancerous condition in their breast ducts who underwent lumpectomies experienced a startlingly higher recurrence rate of cancer in the operated breast—39 percent within ten years—despite whatever additional treatment they received.

In contrast, the Boston lumpectomy patients who didn't have the precancerous breast duct condition had only a 3 or 4 percent same-breast recurrence rate in the same time period. In total "about a third of the patients have extensive intraductal tumors," Harris explained, "and it's more common in young women. It's directly related to age." Though the Boston doctors feel confident of their findings, other major researchers do not agree. As with everything pertaining to breast cancer, nothing is certain.

Had the Boston research been available when I was first diagnosed, I could have been told about the study. I would have judged the odds too high. Having a breast for two more years was not worth going through the cancer treatment regimen twice. I would have had the mastectomy in the first place. But I do not speak for everyone in that predicament.

"You can't judge for other people," said Susan Love, a Boston breast surgeon. "There are people who would rather have just a lumpectomy [without radiation]. I have patients with a mortal fear of radiation, and they don't want to be nuked. I have women who say, 'Thank you very much, 80 percent is pretty good odds.'" It is not reassuring when the best doctors, who have read or conducted every major published study on the subject and have personally treated as many as 700 breast cancer patients, are as unsure about the outcome of treatment as you are.

Hellman, of Memorial Sloan-Kettering, said one of his greatest quandaries now concerns the patient with no palpable disease but whose mammogram may show evidence of the precancerous condition in the breast ducts. Mastectomy would virtually guarantee cure. Radiation might work as well, but the chance of recurrence would be greater by whatever small percentage point. "Can you imagine," he asked, "having to tell a patient her disease is so early that the surest course is to remove the breast?"

Doctors also feel uneasy about the well-acknowledged fact that when they perform a lumpectomy they can vastly underestimate the amount of cancer left behind in the operated breast, even after obtaining a good margin of clean tissue around the lesion. How dangerous the cancer left behind is to the patient is an open question. "There is some circumstantial evidence around to make you think that it doesn't matter," said Love. "There certainly is data to make you think that local failure in the breast probably doesn't impact on survival."

Other cancer specialists disagree. Michael Osborne, my breast surgeon at Sloan-Kettering, said he found it "very hard to conceive that having a little cancer in the breast is not a bad thing and that effective local treatment is never going to make a difference to a patient and that recurrence couldn't go ahead and spread in its own right." Marc Lippman, head of the National Cancer Institute's breast cancer section, says, "Treating recurrent breast cancer is a nightmare. There are a lot of ways to die, and breast cancer, uncontrollable chest wall breast cancer, is among the least attractive. So the concerns people feel getting adequate local control are very, very cogent and realistic."

Another difficulty for a patient who has undergone partial surgery and radiation is actually being able to detect a recurrence if it happens. The redness, tenderness, pain, hardness and changes on the mammograms after the procedures can be confusing.

I had become ineffective at self-examination and left it to my oncologist. It was my good fortune that the doctor who treated me in Jerusalem, Zvi Fuks, became chairman of radiation oncology at Memorial Sloan-Kettering at the same time I moved to New York. Neither of us wanted to believe the new mass was anything but scar tissue. A needle biopsy made it clear we were wrong.

I had been warned that a recurrence was a distinct, albeit remote, possibility, so I came to terms with having a mastectomy with less angst than most. What was killing was the consensus of all the specialists we checked with that the second, more aggressive, course of chemotherapy was necessary. It made clear something I preferred not to think about: that breast cancer is a disease that can come back again and again.

It is at least comforting to know that the research continues. The Boston group is conducting a clinical trial to determine which women might be candidates for lumpectomy alone—with no accompanying radiation or chemotherapy. The National Cancer Institute is also conducting a study to assess which women are the best candidates for what treatment. So far, finding enough women patients willing to participate has been difficult, even though treatment at the National Institute of Health, in Bethesda, is both excellent and provided without charge.

"There are 130,000 breast cancer cases every year, and more than 100,000 of them would qualify for this trial," says Lippman, the study's leader. "If I had 1 percent of that population, I would close the study within six months and be able to answer the questions in several years."

It would be good to have those questions answered because here, in the 12 percent, the statistics and percentages mean very little indeed.

Despite the uneven relief of my chest, I did summon the whatever-it-is-one-summons to buy this strapless black lace dress.

For now, things go well. My hair has all grown back, and my only reminder of a more difficult time is the uneven relief of my chest. I find it amusing and rather a bonus that only one armpit requires shaving, that two hours of tennis leaves only half a T-shirt wet. Yet shopping for a bathing suit has been dismal; the locker room, a furnace of humiliation. Even before breast reconstruction, I did summon the whatever-it-is-one-summons to buy a strapless black lace dress for my thirty-eighth birthday. The alterations lady with the Italian accent built a contour out of white cotton fluff into the right side of the bodice and reinforced the waistline with an internal elastic belt so I wouldn't have to worry about it falling down. Her sister had undergone a mastectomy two years before so she knew exactly what to do. It was amazing, really, and the first time in almost three years I had been able to wear anything besides a nightgown without a prosthesis.

I did not need the new dress. But when I saw that it came high enough not to expose cleavage, my husband and I decided I should have it. I mean, why not?

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