More and more women are choosing to have double mastectomies in hopes of lowering their risk of breast cancer. What have they gained? And what have they lost?
Last May, actor and activist Angelina Jolie, who’d never been diagnosed with breast cancer, announced she’d had a preventive double mastectomy—surgical removal of her healthy breasts to greatly reduce her chances of developing breast cancer. But while she was perhaps the most famous woman ever to undergo the procedure, even before her announcement there had been a significant uptick in the number of women opting for the surgery, a total that her revelation only increased, say medical experts.

For women like Jolie, who have an unusually high risk of developing the disease because they carry a mutation in the BRCA1 or BRCA2 gene, the radical choice can be lifesaving: Double mastectomies reduce the likelihood of breast cancer by more than 90 percent, making the procedure far more effective than any other option available to women at genetic risk. But not everyone who gets preventive surgery is facing the same grim odds as Jolie. An increasing number of women who’ve been diagnosed with cancer in one breast—many of whom would be prime candidates for lumpectomy and radiation—are having both breasts removed, as are many women with the early, low-risk cellular changes known as DCIS. For women without strong genetic risks, is preventive double mastectomy an unnecessarily extreme step? Or are they justified in thinking, Better safe than sorry? Here’s what you should know to figure out what’s right for you.

If you are at high risk but disease free

A number of factors can boost your breast-cancer risk above 12 percent, the average for most women. An estimated 400,000 women in the U.S. carry a mutation that causes a malfunction in the BRCA1 or BRCA2 gene, which ordinarily produces proteins that suppress uncontrolled cell growth. The BRCA1 mutation is the more dangerous one; it is linked with triple-negative breast cancer, an aggressive form that’s hard to stop because it doesn’t respond to some of the most effective treatments. These hereditary mutations are responsible for 5 to 10 percent of all breast-cancer cases and put an individual’s risk of developing the disease at anywhere from 45 percent to 80 percent.

For women who carry the mutation, a double mastectomy is known not only to reduce dangerously high risk but also to relieve the substantial anxiety that comes from living with perilous odds. When the MD Anderson Cancer Center surveyed women who are “mutation carriers,” the majority said they viewed preventive mastectomy as the only way to reduce their worries.

Although there are no large-scale studies on the rates of prophylactic mastectomy in BRCA-mutation carriers, researchers at Cedars-Sinai Medical Genetics Institute published a small study last year on women with the BRCA mutation who were counseled at their center from 1998 to 2010. Of the 136 women who carried the mutation but had never been diagnosed with breast cancer, 42 percent underwent prophylactic mastectomies. The defining characteristic of those who opted for the surgery? Having a first-degree (mother, sister or daughter) or second-degree (aunt, niece or grandmother) relative who died of breast cancer.

“Watching a loved one die or go through a difficult battle with this disease makes women more likely to take extreme measures to avoid it,” says Deanna Attai, MD, a breast surgeon at the Center for
Breast Care in Burbank, California. And then there’s the Angelina Factor. “Since Jolie’s announcement, I definitely have more BRCA patients wanting to discuss surgery,” Attai notes. “Many patients’ families criticized their desire to undergo prophylactic surgery, and Jolie has given them validation.” Karen Kramer, vice president of marketing at FORCE, a nonprofit organization for BRCA-mutation carriers, agrees: “Angelina has destigmatized prophylactic mastectomy.”

Some factors in addition to the BRCA mutation boost the risk for cancer, but not all of them greatly raise the danger level. Dense breast tissue and less common changes in certain genes—including the ATM gene, which helps repair damaged DNA, and the TP53 gene, which helps stop the growth of abnormal cells—all hike risk somewhat but usually not enough to compel consideration of a preventive mastectomy. Family history is a bigger concern. “If two or three close relatives—a sister, mother or grandmother—were diagnosed before they turned 50, you’re at very high risk whether you carry the BRCA gene or not,” says Susan Domchek, MD, executive director of the Basser Research Center for BRCA at the University of Pennsylvania’s Abramson Cancer Center. “That doesn’t mean you need preventive surgery, but it’s one option on the table.” A genetic counselor can help you gain insight into how your profile stacks up. “Testing—and interpreting the tests—is complex,” says Ellen Matloff, director of Cancer Genetic Counseling at the Yale Cancer Center.

Alternatives for BRCA carriers

While many experts agree that mastectomy is the safest alternative for many BRCA-mutation carriers and others at high risk, it’s still a drastic step and not the only choice. “Mastectomy is an option, not a mandate—and in mutation carriers who haven’t been diagnosed with breast cancer, there’s no rush to decide,” says Domchek. Keep in mind: A double mastectomy doesn’t ensure that a mutation carrier won’t get breast cancer. “Mastectomy reduces your risk by about 90 percent but doesn’t completely eliminate it,” she explains. Other options can lower risk, too. Having your ovaries removed decreases the odds of breast cancer by 50 percent.

Taking risk-lowering medications like tamoxifen and raloxifene may be helpful as well—probably more so in those with BRCA2 mutations, who are likelier to have tumors fueled by estrogen, a process these drugs can block. BRCA-mutation carriers who don’t have mastectomies should follow a stepped-up surveillance regimen with annual mammograms and MRIs to ensure that if they do develop cancer, it’s found in an early, treatable state. They should also exercise regularly, maintain a healthy weight and minimize alcohol. All of those steps have been shown to offer some protection.

“The decision to have preventive surgery or not is personal, and women need to weigh all the factors: their family history as well as the risk of their specific genetic mutation, plus considerations such as how surgery might affect their body image, their level of anxiety about developing breast cancer and even their current family and work obligations,” says Jennifer Litton, MD, a breast medical oncologist at the MD Anderson Cancer Center.

“Women with a BRCA mutation who don’t have breast cancer have plenty of time to decide what they want to do. Some wait years before making a choice about surgery,” Litton adds. Age matters, too. “If you’re 25 and have the more dangerous BRCA1 mutation, you have a long time to possibly develop breast cancer, so a preventive mastectomy will offer years of protection from a potentially fatal disease,” says Domchek.

She continues: “For women in midlife who haven’t yet been diagnosed with breast cancer, it’s fine to go with prophylactic mastectomy—but it’s probably as protective to instead have your ovaries removed and get regular screening with MRIs.”
If you’ve been diagnosed with cancer in one breast

A DECADE AGO, lumpectomy with radiation was the usual treatment. Now an increasing number of women who are diagnosed with cancer in one breast are choosing to have both removed—the healthy one along with the cancerous one. In the largest study to date, published in 2007, researchers at the University of Minnesota looked at more than 150,000 women with cancer in one breast and found that over the six years of the study, the rate of double mastectomy nearly tripled, from 4 percent to 11 percent. In 2010, researchers at the MD Anderson Cancer Center confirmed the trend: In the span of seven years, the percentage of women with cancer who opted to have a double mastectomy shot from 7 percent to 14 percent, and most of those who underwent the procedure didn’t have a known genetic predisposition to the disease.

Among women with DCIS, a non-invasive condition in which abnormal cells are confined to the milk ducts, double mastectomy has increased to almost 20 percent—a rate that is too high, says Todd Tuttle, MD, chief of surgical oncology at the University of Minnesota Medical School. “The 10-year risk of getting DCIS or invasive cancer in the healthy breast is low—about 5 percent,” Tuttle says. (For a patient’s view, see “I Could Not Live with the Worry That My Stage-0 Cancer Would Recurr,” opposite.)

Why are so many women opting for preventive surgery? “Women who’ve been diagnosed with breast cancer are worried about having to go through the experience again down the road, and double mastectomy seems like the safest way to prevent a repeat bout,” Litton says. But this drastic surgery may not be the most appropriate path, given its low benefits. For one thing, the chance of getting cancer in the unaffected breast is far lower than most patients believe. In a University of Minnesota survey, women who had cancer in one breast put their odds of getting cancer in the unaffected breast at over 30 percent. The actual risk? Four to 5 percent, says Tuttle, the study’s lead author. Another recent survey of breast-cancer survivors who opted for double mastectomy found that 94 percent made the choice partly to improve their chances of survival. “The trouble is, having a healthy breast removed doesn’t improve your survival rate one bit,” says Tuttle, who has done research on these outcomes.

“Breast cancer doesn’t usually develop in the other breast,” he explains. “It spreads to the lungs or liver or bones or brain. Having a double mastectomy doesn’t affect those more likely problems at all. Most women could be as effectively treated with lumpectomy and radiation.” That approach might leave some women with lingering anxiety, acknowledges Dianne Shumay, PhD, associate director of psycho-oncology at the Helen Diller Family Comprehensive Cancer Center in San Francisco. “Fear and worry don’t respond to logical argument—and our research has shown that there’s not a linear relationship between level of risk and amount of anxiety,” she says. CONTINUED ON PAGE 122

“I was battling an aggressive cancer.”

CASSANDRA LEVINE, 57
Baltimore

THE CANCEROUS NODULE was small, about the size of an M&M, the doctor said—not a peanut M&M but a chocolate one. It was embedded deep in the breast duct, which was why I’d never felt it and why the technician who did the follow-up mammogram had needed to press so hard, and painfully, on my left breast to get a clear image.

Two weeks later, I had a biopsy. When I met with Dr. Dawn Leonard, medical director of the Herman & Walter Samuelson Breast Care Center at Northwest Hospital in Baltimore, I got the diagnosis: poorly differentiated invasive ductal carcinoma. I had an aggressive cancer that was more likely than other types of cancer to return. If I did nothing, I’d probably be dead in 10 years. But since the cancer was so small, my chances of long-term survival were 98 percent whether I had a lumpectomy or a mastectomy, single or double. Dr. Leonard never tried to influence me one way or another.

It was an entirely different experience when I went to get a second opinion from another surgeon. After I told him I was considering having both breasts removed, his response was, “Why would you want to do that? It took you 53 years to get breast cancer in your left breast. It could take another 53 years to get cancer in your other breast.” I thanked him for his time and left.

Deciding on the treatment with Dr. Leonard was easy. I’ve never smoked, I don’t drink alcohol, I work out six days a week for an hour or more. I do everything I can to stay healthy, and I did not want to risk a recurrence in the noncancerous breast. My “girls” had turned on me—they had to go. Plus, if I chose lumpectomy, I’d probably need 35 rounds of radiation. I wanted to avoid any procedures that are designed to save your life but can do a lot of damage in the process.

Dr. Leonard did the mastectomy, and another doctor performed reconstruction with temporary expanders. The final pathology report said I had what’s called triple-negative cancer, which is more common in African-American women like me. This type does not respond to targeted drugs like tamoxifen or Herceptin, so I needed four rounds of chemotherapy to wipe out any stray cancer cells.

I feel wonderful today. I actually had my C-cup implants changed; they were getting in the way of exercise, so I swapped them for B cups. Twice a year I see my oncologist, who draws blood to see if there are any markers indicating that the cancer is returning. For the first 18 months after the mastectomy, those appointments made me anxious, but now I look forward to them. The news is always good, and it’s exciting to get confirmation that I’m as healthy as I feel. —AS TOLD TO S.L.
Hank and the landlady sit together, drinking fruit shakes and listening gamely as I try to unravel why we’ve come. I explain how this place made a dramatic impression on me—a superficial version of the truth—and I am curious to find how it strikes me now. I recall some of the happier scenes: My sister and I gathered eggs from underneath the chickens in their coops every day, offering an anchoring sense of routine during our stay. We played often in what felt like our very own forest, with a row of trees creating a shady roof of leaves.

The three of us wait for the rain to subside—there have been daily downpours, living up to the Ireland stereotype—and then venture forth. Nothing feels familiar enough to hang on to as a guidepost. I see hens and geese in a fenced-off part of the property, but I can’t tell where we might have gone to gather the eggs. There is no forest either, although we do walk across a field with a scattering of trees that offers a caress of familiarity.

When we finally arrive at the house, however, things start to come into focus. We walk into the dining room, a long, narrow space with large French doors opening out onto the garden, and I feel a flush of recognition and relief. This is the room of my memory—where I ran through the doors to play. I feel a flush of recognition and relief.

In my mind, though, the rest of the place had been all white walls and sharp angles, stern and sophisticated in the way that modern houses arrange themselves. But as we walk around, I realize that’s not quite right. The house is as bright as I remember, with sunlight pouring in, but is not as architecturally severe. We go upstairs. I find my old bedroom. I stand at the spot where we sat for dinner, where I greeted my cousins when they came to visit, where I ran through the doors to play.

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Is there value in re-encountering places from your history? I feel the experience fell short of what I’d expected. The flash of recognition in the dining room had offered a moment’s revelation, but it wasn’t sustained. Other people lived in the house now; we were in the way. My stomach hurt. Hank’s shoes were wet from the rain. In the smoky corridors of the mind, such realities are excluded; memory is exalted.

Later that week, we go for a drive around county Kilkenny—the region that includes both Kilkenny City and Thomastown, among other places along the river Nore—and come upon the most spectacular views. We pull the car over and look out at the great patchwork of green sloping down the hills and across the rolling land. Some of the surrounding tiny towns—Knocktopher, Bennettsbridge and Graignamanagh—are age worn but still have those defiantly optimistic, brightly colored doors.

We go to the ruins of Jerpoint Abbey, a Cistercian monastery of the 12th century. It’s raining again, which makes everything more beautiful; the weathered gravestones scattered higgledy-piggledy across the vibrant grass glisten. As I walk among the dead, I think about the disappointment of my return, its stubborn refusal to yield more.

But then, slowly, over the course of our last days there, disparate thoughts come together to offer meaning. I’d hoped to use memory to travel backward through life. I’d wanted another chance with myself as a child with young parents; I’d aspired to some kind of reconciliation. Instead, I learned that I could not provoke or manipulate my memory by revisiting its actual landscape—and also that I needn’t have tried. This place holds far more power, and promise, in the grainy footage of my seeing it in the world again.

NELL CASEY edited The Journals of Spalding Gray. She lives in Rome with her husband and two children.

Mastectomies

The aftermath of surgery

What are the pros and cons of surgery? “On the plus side, mastectomy and reconstruction techniques have improved—and it’s easier to create symmetrical breasts if you do both sides at the same time,” says Attai. “Many of my patients voice concern about the symmetry issue.”

The minuses: The surgery is major—most women can’t return to work for six to eight weeks. Reconstruction, if performed, brings a host of potential complications, including infection, leaky implants and capsular contracture, a condition in which the tissue around the implant becomes hard and painful. “I tell patients they have a 40 to 50 percent chance of needing a follow-up operation,” says Attai.

If a doctor recommends surgery, it will probably be covered by insurance; if she doesn’t, you may have to pay out of pocket, and if you have both mastectomy and reconstruction, the cost will be substantial—upwards of $20,000. Moreover, even when surgeons perform the nipple-sparing version of the procedure, the reconstructed breasts will look natural but will still lack sensation. “That can be a blow to both your body image and your sexuality,” says Susan Love, MD, founder of the Dr. Susan Love Research Foundation and author of Dr. Susan Love’s Breast Book. When researchers at the Mayo Clinic followed up with breast-cancer survivors who had chosen to have a double mastectomy, a quarter of the women said the surgery had had a negative impact on their sexual relationships and their feelings of femininity.

Still, a number of studies show that most women who have preventive mastectomies are happy with their choice. “They may feel reassured by the fact that they’ve been aggressive about trying to fend off a recurrence,” says Tuttle. Then again, those who opt for lumpectomy and radiation say they’re satisfied, too. “The key factor seems to be feeling as if you made an informed decision,” Litton says. “That matters more than which option you chose.”