

A Preemptive Strike Against Breast Cancer

Why more women are proactively choosing to have a double mastectomy.



Arlingtonian Allie Ferrari (right) and breast surgeon Molly Sebastian. Photo by Liz Lynch.

Five years ago, Allie Ferrari watched her 65-year-old mother suffer through a breast cancer diagnosis and treatment. She stood by supportively as her mom endured the physical toll of radiation and grappled with a slew of potentially life-or-death medical decisions—plus the fear of not knowing whether she would survive.

Her mom did survive. But bearing witness to that struggle steeled Ferrari's resolve to not go through the same thing. Ferrari started haranguing her insurance company until it finally relented and covered testing for a gene mutation that indicates high risk of breast and ovarian cancer.

She tested positive. With that risk looming over her, Ferrari, now 46, pushed aside her tears and decided to get the worry off her chest—quite literally. She had a preemptive double mastectomy last year.

Preemptive (also called prophylactic, preventive or risk-reducing) mastectomies have become more popular as breast reconstruction techniques have improved, genetic testing has become more accessible and women have begun to feel empowered to speak openly.

Breast cancer was once a topic no one talked about, but that taboo has been swept away in a breeze of pink ribbons. Newscasters and celebrities have come forward to tell their personal stories. Actress Angelina Jolie's decision to go public about her own double mastectomy in 2013—after learning she has a faulty gene that greatly increased her odds of getting breast cancer—made many women realize they didn't have to be victims.

In the U.S., breast cancer is the second most common type of cancer in women (after skin cancer) and the second-deadliest cancer killer of women (behind lung cancer), according to the National Cancer Institute. Men also can get the disease, though women are 100 times more likely.

This year, almost 41,000 women will die from breast cancer, according to the American Cancer Society.

Although less than 10 percent of cancers are believed to be caused by inherited mutations like the BRCA gene that Jolie carries, cancers stemming from such mutations can be particularly hard to treat. To avoid that ordeal, a growing number of women who test positive for genetic variants are choosing to have both breasts removed before they are ever diagnosed with cancer. Others are requesting a double mastectomy as a safeguard even when a malignancy is found in only one breast.

The shift has been notable, says Molly Sebastian, a breast surgeon and medical director of the Reinsch Pierce Family Center for Breast Health at Virginia Hospital Center. Sebastian estimates that five years ago she did one prophylactic mastectomy every three to six months. Now the number is up to two a month.

Ferrari was found to have BRCA2, one of the two best known gene mutations that can lead to breast cancer (Jolie had BRCA1). Under normal conditions, BRCA genes are supposed to produce proteins that suppress tumors. But when they are faulty, the risk of developing ovarian or breast cancer increases. A child of a mother or father with the faulty gene has a 50 percent chance of also having the mutation, which can cause cancer and/or be passed along to their offspring, according to the National Cancer Institute.

Genetic testing for breast and ovarian cancer is on the rise. A 2016 study led by Sunita Desai, then a health care policy fellow at Harvard Medical School, showed a 64 percent increase in such testing in the U.S. after Jolie's announcement.

Celebrity testimonials do tend to push certain health risks into the spotlight, but the uptick is also a reflection of testing becoming more widely available and affordable, says Sebastian, who chairs the genetics committee for the American Society of Breast Surgeons. A 2013 Supreme Court decision opened up more competition among testing labs, driving costs down and quality up.

Though online tests are now available for about \$250, Sebastian says the larger labs that most breast centers use (which charge about \$1,500 for a full screening) produce more reliable results.

Most insurance companies now cover genetic testing for those with certain risk factors, such as having contracted breast cancer before age 50; having three or more family members with breast cancer; having both breast and ovarian cancer in the family; and/or Ashkenazi Jewish heritage.

Choosing to have a double mastectomy may seem like a radical move, but for patients at higher risk, it alleviates the heart-stopping cycle of mammograms they fear will be their death warrants. "Once you get the BRCA diagnosis, you constantly think cancer, cancer, cancer," says Ferrari, a federal government immigration lawyer, who lives in Arlington's Rock Spring neighborhood with her husband and son.

Ferrari made her decision quickly after she found out in 2016 that she carried the defective gene.

"I'm a lawyer. I'm very logical. As soon as I get bad news, I act," she says. "Once I got the diagnosis...I felt like a ticking time bomb. Do you know how hard it would be to tell my 12-year-old I have cancer?"

She had an oophorectomy to remove her ovaries and fallopian tubes just one month after the bad-news test; then the double mastectomy in February 2017.

Losing a third family member to breast cancer is what finally compelled Elizabeth (not her real name), 49-year-old Ballston resident, to seek genetic counseling and, ultimately, a double mastectomy.

Her mother and grandmother both had died young of breast cancer. When a cousin close to her age died from the disease in 2015, she got tested. Not only did she have the BRCA1 gene, but her levels of the protein CA-125 were elevated, indicating that she might have a higher risk of ovarian cancer.

Today, physicians are spending more time helping women weigh their options. Each case is different. The decision might not be the same for an 80-year-old, for instance, as it is for a 35-year-old, given the lifetime odds of cancer weighed against the risk of any surgery, says Neelima Denduluri, a Virginia Hospital Center oncologist who specializes in breast cancer treatment. "It's a very personal choice," she says.

FACTS ABOUT BRCA

- BRCA1 and BRCA2 are genes whose job is to produce proteins that suppress tumors. Those proteins are important because they fix damaged DNA. But some people have defective BRCA genes that don't do their job, leaving cells vulnerable to breast and ovarian cancer.
- Genetic testing can help patients find out whether they have the faulty genes, and therefore a higher chance of getting cancer and/or passing the propensity along to offspring.
- Not everyone who gets breast cancer has the faulty genes. In fact, only 5 to 10 percent of all breast cancers involve these genes.
- BRCA mutations aren't the only villains in hereditary breast cancer. Researchers are finding other, less common genetic variations that also are linked to higher rates of breast cancer, such as CHEK10 and ATM. "For 25 years we only talked about BRCA1 and BRCA2," says breast surgeon Molly Sebastian. "Now they can test for as many as 60 different gene mutations."

Surgery is not without risk. With it comes the possibility of infection—especially if breast reconstruction includes implants—as well as blood clots, pneumonia, and skin issues or scarring that require further surgery.

There's also a time factor. The initial recovery period lasts about six weeks on average. Some women have a mastectomy and reconstruction at the same time, while others do them as separate procedures.

BRCA RISK FACTORS



Though a bilateral mastectomy is not a guarantee against future breast cancer, it does lower the odds significantly, to about 5 to 10 percent, according to the National Cancer Institute.

"It turns out I had early-stage ovarian cancer," says Elizabeth, a federal government employee, who is single. "I was very, very lucky because usually it's not found at that stage because there are no symptoms."

Still, some doctors worry the pendulum has swung too far, prompting certain patients to request mastectomies that are unwarranted. Surgery probably isn't needed for someone with, say, a 17 percent risk of getting breast cancer, says Sebastian. "Medically you've got to have evidence of a true cancer risk."

After a hysterectomy and chemotherapy to get rid of the ovarian cancer, she was determined to do whatever she could to avoid breast cancer, so she had a double mastectomy in October 2016.

Having both breasts removed when cancer is found in one breast also doesn't diminish the risk of the original cancer coming back in another part of the body, Denduluri says, citing a study in the journal *Annals of Surgery* in March 2017. Yet that same study found that the rate of women opting for preventive mastectomies in the cancer-free breast tripled from 3.9 percent in 2002 to 12.7 percent in 2012.

When the post-op pathology report showed no diseased breast tissue, she says she felt a twinge of regret—that perhaps the mastectomy had been unnecessary. But she's mostly relieved to be unburdened of the fear that had moved to the front of her consciousness. "The risk is not completely gone, but it's so small now, whereas before it was so high," she says. "In the end I'm glad I did it."

Otis Brawley, chief medical and scientific officer of the American Cancer Society, says certain women may be seeking prophylactic mastectomies prematurely after their test results show genetic anomalies with unknown risk factors. Some anomalies are best described as minor “spelling errors” in the genome sequence, he explains, but don’t mean higher cancer risk. He recalls one patient who had a double mastectomy after receiving an abnormal test result, and was devastated six years later when researchers determined that it wasn’t a mutation after all—just one of those spelling-type anomalies.

“We’re concerned some women are getting this procedure and not understanding what their risk really is,” says Brawley, an oncologist and professor at Emory University Medical School, when they may be better served by nonsurgical alternatives, such as medications like raloxifene, which treats osteoporosis but also reduces breast cancer risk. “It really is a complicated business where people need to go to the experts.”

It’s tough to know exactly how many women are opting for preemptive double mastectomies, he adds. While patients with a cancer diagnosis have their medical information logged into oncology databases, healthy women who have the procedure as a preventive measure are not tracked.

But there is evidence that more women are going this route. A 2008 survey published in the *International Journal of Cancer* found the practice more common in the U.S. than in any of the other eight countries in the study.

Statistical probabilities are seldom the only factor weighing into a woman’s decision about whether to have both breasts removed. For many, it’s also an emotional choice.



Falls Church resident Rebecca Fannin had surgery in April.

As due diligence, she followed up with a comprehensive genetic screening. The tests indicated no increased risk for other types of cancer.

“Then, about two years ago, my maternal aunt had a second recurrence of cancer in her other breast, which was a new concern,” says Fannin, a PR executive who lives in Falls Church City. “That changed how I felt about my own risk. From a statistical standpoint it didn’t jump me into another risk category, but there was an emotional weight and it wasn’t just on me. It affected my husband, Luke, too. To have that fear all the time—it felt heavy.”

On April 11, 2018, Fannin checked into Virginia Hospital Center for a double mastectomy. Like Ferrari’s, her care team included Sebastian as her surgeon and Denduluri as her oncologist. Later this summer, she’ll return for a second (reconstructive) surgery.

Advances in reconstructive surgery have removed a big stumbling block for women who previously wouldn’t have considered a mastectomy that would leave them flat-chested, says Sarosh Zafar, a plastic surgeon at Virginia Hospital Center who will be relocating later this summer.

The latest implants are more natural looking, helping to alleviate some women's feeling that they've lost part of their feminine identity.

Plus, certain patients have the option of reconstructing new breasts using their own tissue. In a procedure known as "free flap" breast reconstruction, abdominal tissue taken from below the belly button is used to create new breasts. This approach bypasses the complications associated with implants—such as the possibility of rejection and the need to replace the implants every 10 to 15 years—but it can require follow-up surgeries. Some women may not be candidates if they don't have enough belly fat to spare.

Under a 1998 federal law, most group insurance plans must cover reconstruction if they cover mastectomy.

But recovering from a prophylactic double mastectomy is no picnic. "The first days you feel like you've been hit by a Mack truck," says Ferrari, recalling the pain and pressure.

After surgery, patients must wear drainage pumps to take fluids out of the surgical site. Elizabeth remembers not having enough upper body strength to walk her beagle. Four or five months out, she still couldn't lift a suitcase above her head, though her strength now—18 months later—is coming back with weight lifting and physical therapy.

There are other side effects, too. While reconstructive surgery left Elizabeth's breasts looking like they did before, she has lost sensation in them. "That's a pretty big downside," she says.

Women generally lose feeling in the center of their breasts after mastectomy, Zafar explains, because the nerves are cut out along with tissue, though some women regain feeling if their nerves regenerate.

Fannin, whose surgery is still fresh, says the greatest stress beforehand was not knowing what her body will look like. "You're in a Frankenstein phase for a while," she says, "but it's been better than I thought. I'll live with feeling strange for a couple more months—which means going back to work and not wearing regular clothes. But I know I'll start feeling and looking more like my regular self with time."