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Sisters Act

Sisters Jennifer Arnold and Kristen Worden have always been close—but never more so than when one was diagnosed with breast cancer and the other chose elective surgery to escape the same fate. **By Judith Newman**



Jennifer (left) and Kristen (right) with their sister, Carrie, in the Cayman Islands in 1996

Over cocktails in Overland Park, Kansas, Jennifer Arnold and Kristen Worden are good-naturedly bickering. They're sisters, so this is sort of their hobby.

"I'm a little pissed that hers ended up bigger than mine," says Kristen with a smile. "It's not fair."

"My skin was stretchier," Jennifer says, sipping her margarita.

"But still, it's not fair," Kristen insists. "You got to fill yours bigger because you had all that extra skin.

"[The doctor] said, 'I don't know much about this. All I can say is, everyone's terminal.'"

Next time, I'm getting bigger ones."

"We'll see," says Jennifer coolly.

The objects of today's sibling rivalry are the women's newly reconstructed breasts. However much they are kidding (or not) about the competition, this much is certain: They are damn glad they are alive to be having this argument. Earlier this year, when Angelina Jolie announced that

she'd had a double mastectomy after discovering she carried the BRCA1 gene mutation, the world applauded her honesty for talking about it publicly. So did Kristen, 36, and Jennifer, 38. But their admiration had another facet to it. Five years ago, they faced a similar dilemma when one sister was diagnosed with breast cancer and the other tested positive for the

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gene mutation that can cause it. To the public, Jolie may have looked heroic; to these sisters, she looked like a woman with common sense.

Since they were toddlers, Jennifer and Kristen have been unusually close. They didn't look alike—Kristen was heart-faced and cherubic, while Jennifer had the olive skin and angularity of a Midwestern Cher—but people often mistook them for fraternal twins. They enjoyed dressing alike, took dance classes together, and drove to high school together every day. As adults, they live within a mile of each other. They even schemed to conceive two of their children at the same time, so the kids could grow up being buddies. It worked: Their eight-year-old daughters were born a week apart.

In 2008, their symbiotic relationship would be sorely tested. One day Kristen, who worked for a pharmaceutical company, found a hard lump the size of a gum ball in her left breast. She had been good about self-exams and hadn't felt anything there a month earlier. Her ob-gyn felt there was nothing to worry about, she says, but sent her to have an ultrasound. The diagnosis was benign fibroadenoma. Still, the suddenness of its growth alarmed Kristen. She went to a breast surgeon who agreed with the diagnosis—but Kristen insisted on having it biopsied.

That was on a Wednesday. The following Monday, the surgeon called with the results: "She couldn't believe it, but it was cancer," says Kristen. "I hate to admit that my first question was 'Am I going to lose my hair?' Not 'Will I die?' Just 'How about my hair?'"

Kristen would have to wait two days before she could see the surgeon again, and when you've just

gotten that diagnosis, two days can seem like two years. Kristen called Jennifer. Jennifer is not known for her patience, so she assumed her older-sister pitbull role and got an appointment the next day with an ob-gyn. As it turns out, this guy would not be eligible for any Dr. Sensitivity awards, either. Kristen asked if she would die. He turned to her and said, "I don't know much about this. All I can say is, everyone's terminal."

Breast cancer had been rife in their father's family; his mother had died of it, as had various aunts. But Kristen and Jennifer had never focused on that part of their family history. "People often don't know this, because the fathers rarely get breast cancer, but you can inherit the BRCA gene from your mom or dad," says Marilee K. McGinness, an assistant professor of surgery at the University of Kansas Medical Center and the breast-cancer specialist who treated both sisters.

There was more painful news to come. Kristen's tumor was triple negative, meaning her cells did not have receptors for estrogen, progesterone, or the HER2 protein. "I started Googling. That was a bad idea—don't ever Google," she says. Triple-negative cancer, she learned, does not respond to newer, targeted treatments that are specific to those hormones or HER2. (Oncologists generally say it can be more aggressive.) Triple-negative breast cancer is often found in



Jennifer (left) and Kristen in 1980

patients with the BRCA gene mutation, and once Kristen tested positive for the faulty gene, it only made sense to test the rest of her family. Kristen and Jennifer's older sister, Carrie, didn't have the mutation. But Jennifer and their father did.

Jennifer was already devastated by her younger sister's cancer. And now here she was, 32, going from a life of normalcy to thinking her body was a ticking bomb.

The choices she was given were stark: Keep her breasts, and she would have a 50 to 87 percent chance of developing breast cancer in her lifetime, as compared with 7 percent for the general population. Those odds were reduced by about 90 percent with mastectomy. Her chance of contracting ovarian cancer was 35 to 46 percent, as compared with less than 2 percent for the average woman. If she removed her ovaries, she would reduce her risk for ovarian cancer by 96 percent. Some people can cope with constant uncertainty; Jennifer couldn't. She decided that, as they had so many times before, she and her sister would travel together.

Kristen's cancer was diagnosed in April; May was devoted to tests to make sure it hadn't spread. Her doctors decided to shrink the tumor and kill off any outlying cells before removing her breasts. "It's hard to live for months knowing you still have cancer inside you," she says. June through September was chemo season, with a cocktail of Adriamycin and Cytoxan injected into the port implanted in her chest once every two weeks for eight weeks. Hair gone after two weeks. Then 12 weeks of Taxol, another chemotherapy agent.

Kristen did not really look frail, though. "Between the casseroles that everyone was bringing to our house and the fact that the chemotherapy put me into menopause, I gained about 60 pounds," she says. "Even with chemo,

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eating was not a problem for me.” One time her husband, Travis, who had accompanied her to an appointment, looked at her compared with many of the people there who were emaciated and whispered to his wife, “Are you getting the chemo supersized?” “Which made me want to kill him but cracked me up, too,” she says.

By October, Kristen was ready for the double mastectomy at the University of Kansas Medical Center. Looking back, she realized she hadn’t prepared herself for the physical transformation. “KU is a teaching hospital, and I just remember I was bloated, bald, pale, flat as a board...and they had, like, the hottest residents. At a certain point, I was like, Seriously, can you bring in some people who aren’t good-looking?”

Jennifer was also ready to get on with her surgery, but she delayed it because of her sister. She wanted Kristen to feel better, maybe to need her just a little bit less. “Kristen can be much more emotional and dramatic about things. If the tables were turned and I had cancer, I don’t know if I’d want anyone with me [at appointments],” Jennifer tells me after Kristen has left the room. “I need to feel in control.”

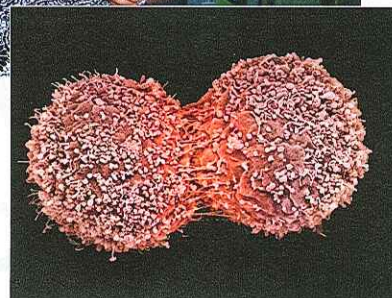
Jennifer organized her surgeries around Kristen’s. Kristen had her mastectomy in October, and Jennifer had hers in November. Then Kristen had a complete hysterectomy, as well as ovary removal, in early December; Jennifer had the same done in January. They went together for their breast reconstruction appointments, where saline was placed in expanders to stretch their skin in preparation for silicone implants. Then, on February 13, 2009, they got their tissue expanders removed and the breast implants put in—together. “Yeah,” said Jennifer, “it was like, ‘Happy Valentine’s Day, girls! *Aww*, here’s your boobs!’”

Ovary removal used to be a more difficult surgery than breast remov-



Jennifer and Kristen at a 2010 Young Survival Coalition fund-raiser in Overland Park, Kansas

“I hate to admit that my first question was ‘Am I going to lose my hair?’ Not ‘Will I die?’”



A magnified image of human breast-cancer cells dividing

al, with a recovery period of around eight weeks. But the laparoscopic procedure both women had, using a Da Vinci robot, makes only tiny incisions in the abdomen and groin. It involves a somewhat longer time on the operating table, but (at least in their case) a vastly shorter recovery time. “By the end of the second week,” says Jennifer, “I was refinishing my bathroom.”

With reconstructive surgery, their breasts could be made whole again. Neither was ready for the physical and emotional fallout of a hysterectomy, though. Kristen went into menopause gradually, but for Jennifer the changes—hot flashes, sleeplessness—happened overnight. “Neither of us has had to wear a coat since we had this surgery,” jokes Jennifer. “It’s not just hot flashes—it’s like perma-flash. You could fry an egg on my back right now.”

The sisters did not have hormone replacement therapy, they say, because of concerns that it might heighten the risk for cancer. (This is a hotly debated topic in oncology, with no studies proving harm from this type of short-term hormone replacement therapy but also no data proving its long-term safety.) But they didn’t

anticipate the side effects—the little brain glitches, the mood swings. “People think you’re fine when you go back to work,” says Kristen. “But for me the combination of chemo and menopause wreaked havoc with my memory.” Jennifer agrees, adding, “At least Kristen’s menopause was more gradual, because of the chemo first. I think they threw out my patience when they threw out my ovaries.”

But for all this...here they are, two gorgeous (if sweaty) women, very much alive. Kristen is five years cancer-free; while triple-negative cancer can be resistant to treatment, hers was not. Her doctors have told her she doesn’t have to come to see them for scans every six months, or even every year. “But that’s just not my personality,” Kristen says. “I’ll be going back every year...or more.” Jennifer, ever the organizer, got involved in fund-raising for the local chapter of the Young Survival Coalition, and Kristen joined her (unless it was the other way around, as Kristen insists). In the first year that they cochaired its annual In Living Pink event, they raised nearly double the amount as the year before.

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SISTERS ACT

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point, only their father has to get regular mammograms, even though his risk is quite small. And everyone has an opinion about the dramatic decision Jennifer made. "It mostly differs by age," she says. "Women my mother's age are often shocked by what I did electively. But they don't understand

see a lot of counseling for Kristen and me before we tell the kids," says Jennifer. "In all honesty, we keep our fingers crossed that we won't have to. Surely there will be a cure by then."

But again: Kristen and Jennifer are here. Their children have their mothers; their husbands have their wives. Both wom-

"Neither of us has had to wear a coat since we had this surgery. It's not just hot flashes—it's like perma-flash."

en are happy with their bodies—Jennifer loves her cleavage—but neither have gone that extra aesthetic mile. Jolie talked about "nipple delay," a procedure before a mastectomy to increase the chance of saving the nipple. But leaving even the tiniest amount of original breast tissue worried Kristen, so both sisters rejected that approach. Neither chose to have nipples artificially reconstructed, either. It's a process that involves skin grafts and tattooing an areola, "and since they never go down, it's like you're always cold," says Jennifer. Because they wouldn't have sensation there anyway, they didn't see the point of more surgery. Still, they reserve the right to do something in the future. "I'm like, if I'm getting tattoos, it's not going to be a nipple," says Jennifer. "I was thinking maybe I'll tattoo a sun and a moon." "I'd just go for stars," says Kristen. ♦

that the surgery isn't as mutilating as it once was. Younger women have seen really good reconstruction, so they've agreed with me—get them off." After all they've been through, Jennifer would tell this to young women with the gene mutation: "It's about your life, and you have the power to change its course. To be there for your kids, to see your grandkids one day.... For me, there was no way I would risk any of that."

They are still worried when they look ten years down the road—not so much about a recurrence of Kristen's cancer, though there is that possibility, but because of the fear that some part of Kristen's treatment will cause another problem. "After all, you're poisoning yourself to make yourself well," she says. They've also thought a great deal about how they will tell their children about the possibility of having the gene mutation. "I fore-

see a lot of counseling for Kristen and me before we tell the kids," says Jennifer. "In all honesty, we keep our fingers crossed that we won't have to. Surely there will be a cure by then."

But again: Kristen and Jennifer are here. Their children have their mothers; their husbands have their wives. Both wom-



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