# Affordable Options

Many cancer survivors who undergo mastectomy can't afford reconstruction surgery. But help is available.

September 2, 2019 By Kate Ferguson

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Like many women undergoing treatment for breast cancer, Heather Allen just wanted to feel well enough to get through each day. From the start, her doctor had told the 38-year-old married mother of six, who lives in Joliet, Illinois, that she would need breast reconstruction surgery.

Allen was adamant that she wasn't going to undergo any more operations. "I'd already lost my hair, gone through chemo and figured they're just going to take the lump and let it shrink, and then I'd go with that," she says. "The doctors kept telling me that I was triple negative and positive for the BRCA gene, so if I didn't remove both breasts I'd probably end up with breast cancer again. I didn't want to hear it, and I didn't want to believe it. I'd heard about a lot of people not doing reconstruction, so I wasn't going to be that person who did it."

Allen had become acquainted with cancer three years earlier, at age 35, when she learned during a visit to relatives that cancer was ravaging her family. Her mother had ovarian cancer, and her grandmother on her mom's side of the family had breast cancer. As the oldest daughter, Allen was chosen to make all decisions about her mother's care. "It was a terrible time because a week later I was burying my mom; she did not survive," she says.

Her mother's doctors were the ones who convinced Allen to get a mammogram and take the BRCA gene test. Eventually, she spoke with her doctor at great length about her reservations and fears. Allen says her doctor stressed that the removal of her breasts would greatly reduce any chance that her cancer would return. In the end, Allen's desire to stay cancer-free won. "In my mind, if I wanted to be alive and not go through diagnosis and treatment again, I had to go ahead and say this is what I had to do."

Allen also wondered how her husband and children would react to her not having breasts. As she neared the end of her therapy, she thought harder about getting the breast reconstruction surgery.

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"I wasn't even thinking about the fact that implants were going to make me look like I have

breasts," she says. "It was just that I knew that I wouldn't have breasts; therefore, I wasn't even going to look like a woman."

Next, Allen had to negotiate the insurance process. "I'd heard that if you were going to get the surgery done, you needed to find someone who specialized in breast reconstruction because there's a total difference between someone just getting a breast job done and a person who got a double mastectomy and needs to have their breasts reconstructed," she says.

At one point, Allen became so fed up with the search that she almost gave up. The plastic surgeons on her state health insurance plan didn't include breast reconstruction specialists. But her aunt convinced her to keep looking, and she began reaching out to different organizations she found online. After spending almost 24 hours on her computer, Allen found the Alliance in Reconstructive Surgery (AiRS) Foundation. "After all of the searching, they were the only place that I came across that actually talked about breast reconstruction," she says. "It was about one o'clock in the morning, so I waited until the next day to call."

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The AiRS Foundation is a nonprofit organization founded by businesswomen and friends Janet Denlinger and Morgan Hare along with Rod Rohrich, MD, the founding chairman of the department of plastic surgery at the University of Texas Southwestern Medical Center.

Rohrich suggested ways in which the two could make a difference in the lives of women who needed breast reconstruction surgery after mastectomy.

By the time Allen connected with Tamara Sieger, the director of advocacy at AiRS, she'd found a plastic surgeon recommended by her doctor.

"He told me the surgery would cost me about $10,000," she says. "I told him there was no way I could pay him that fee out of my pocket for the surgery. At this point, my husband wasn't even working because he was at home helping to take care of me."

Eventually, the surgeon brought his fee down to $8,000 and asked Allen for $4,000 up front. But the cost was still too high. That's when Sieger stepped in to help and got the funds needed for the surgery to happen.

"I don't know how this woman got it done and how she pulled it off, but within a two-week span, she got my surgery approved," Allen says.

Sieger managed to facilitate Allen's reconstruction surgery thanks to a grant the foundation offers. Grants awarded may range from co-pays to the full cost of surgery.

"Whether you fit within the program's guidelines is all based on income," Allen says. "You have to send in your tax return to show how much money your family makes and the bills from the surgeon to confirm the costs of surgery.

“You’re also asked to write a short piece explaining why you feel you want the surgery and the benefits of you having the operation,” continues Allen. “I was excited about the prospect of getting the chance to actually get the procedure done. I felt like, hey, I’m in control of this, unlike not being in control of anything else having to do with my cancer.”

Allen’s emotions simmered close to the surface when Sieger spoke to her. “I cried on the phone as I was telling her ‘thank you,’” she says. “I couldn’t believe this. Everything had worked out, and I was able to have my surgery. I thought about being able to feel as much of a woman as I could feel.”

The preparation for surgery involved doctors inserting tissue expanders in Allen’s chest. Once these temporary implants have sufficiently stretched the skin and muscle, they’re removed during another operation and replaced with permanent breast implants.

“They feel like bricks on your chest because at that moment they are sitting under your muscle,” she says. “They filled them up weekly with a saltwater solution to stretch my muscle; it was very tight and painful.”

When it came time for the surgery, Allen was very nervous, fighting against a barrage of negative thoughts. “It was that old voice in your head that says, ‘You’re not going to wake up,’” she says.

Allen also considered that she hadn’t been declared cancer-free at that point. In addition, she told herself that her body was still weak and rebuilding after cancer treatment, her hair hadn’t grown back yet and her red blood cell count was still very low.

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“I was very nervous that day, so while I was walking in, I was praying and saying in my head, ‘It’s going to be OK. Everything is going to work out. The surgery is going to go as it should because the doctors know what to do.’”

Besides her doctors and other medical professionals there to conduct the surgery, Allen’s team of supporters included her husband and an aunt. In deference to her strong faith in God, the group formed a prayer circle before the procedure began. “We were all sitting holding hands, and my husband was leading us in prayer,” Allen says.

She says she remembers only that as they prayed, everyone held one another, and she hugged each person in the prayer circle individually.

“And then I woke up,” Allen says. “I never remembered going back into the operating room or anything.”

Still, Allen doesn’t mind not remembering any details about the surgery or what happened while she was under anesthesia. After all, her prayers were answered. She found a way to get her breast reconstruction surgery done right on time.

Breast Reconstruction

A quick Q&A on managing expectations

By Kate Ferguson

Alexes Hazen, MD, a member of the board of the AiRS Foundation and an associate professor of plastic surgery at NYU Langone Health in New York City, answers key questions about breast reconstruction surgery.

What factors determine whether someone is a good candidate for breast reconstruction surgery?

The healthiest patients are the best candidates. Sometimes breast cancer treatment can affect the timing of reconstruction. So, for example, if it's recommended that someone undergo chemotherapy, you wouldn't want to operate on that person while she was undergoing chemo or radiation, but you can do so before or after treatment.

Also, I think somebody who has a sense of what they want in terms of the reconstruction and who's informed makes for a really good candidate.

What can folks realistically expect from breast reconstruction surgery?

Some people think that because they are getting "plastic surgery" that their result is going to be better than how they looked before. They sort of fail to think about the fact that they're losing a breast that has to be reconstructed.

In many cases, people are extremely happy with their results, and they feel really good about the way they look. But we are still having to replace something that is not there.

Purely cosmetic surgery is a very different starting point than breast reconstruction, so I think individuals have to expect that breast reconstruction surgery is not going to make them perfect; their breast is not going to be how it was before.

People must come to terms with that aspect of the procedure.

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