

These Women Had Their Breasts Removed to Thwart Cancer. Then Came the Pain.

In the months following surgery, many women are afflicted by post-mastectomy pain syndrome, which spans from uncomfortable to disabling and can last years.

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Three weeks after Sophia Bassan's mastectomy, she felt a stabbing pain beneath her right armpit. In the following months, painful shocks radiated through her chest and back. Her body became so sensitive that at times she couldn't wear a shirt or lift a fork to her mouth.

Bassan slept sitting up because it hurt to lie down, and she would flinch at the slightest touch.

"I remember thinking I was losing my mind," said Bassan, 43. "One time I was in so much pain that I had to take off my top, and then my cat's tail brushed against my back. I screamed."

Mastectomies are lifesaving surgeries that remove a patient's breasts to treat breast cancer, which affects [1 in 8 American women](#) over their lifetimes, according to the American Cancer Society. Some women also undergo mastectomies as a preventive measure after a genetic test shows they have an increased risk for breast cancer.

In the months following surgery, many women are afflicted by [post-mastectomy pain syndrome](#), or PMPS, which spans from uncomfortable to disabling and can last years.

Yet PMPS is inconsistently diagnosed and treated, leaving women like Bassan in agony as they hunt for relief and struggle to find doctors who take their pain seriously, according to a KFF Health News review of peer-reviewed research studies and interviews with pain specialists, surgeons, patients, and patient advocates.

Another problem is that PMPS is poorly defined, which contributes to the wide range of estimates for how common it is, reaching as high as more than 50% of mastectomy patients, according to studies. Even the low-end estimates, around 10%, would amount to tens of thousands of women.

PMPS care could improve if lawmakers pass the Advancing Women's Health Coverage Act, which was introduced in October to ensure insurance coverage after breast cancer treatment, including

preventive mastectomies. The bill, which does not mention PMPS by name, covers complications including chronic pain. More research would help, but pain research has long been fractured across several [medical specialties](#) and, more recently, has been undermined by the administration of President Donald Trump, who last year proposed deep cuts to research funding at the National Institutes of Health. After Congress rejected those cuts earlier this year, the White House slowed the release of NIH grant money, hindering ongoing and future scientific research.

“I’ve known women who’ve had chronic pain — itching, burning, stabbing pain — for years after mastectomies,” said Kathy Steligo, an [author of multiple books](#) on breast cancer who said she has spoken with hundreds of patients. “Of all the problems, that is probably the one least talked about by surgeons.”

Four mastectomy patients interviewed by KFF Health News told similar stories. In separate interviews, patients said their presurgery consultations did not raise the possibility of post-mastectomy pain syndrome, although each said they had signed forms that may have disclosed the chance of this complication. All said that they felt blindsided by the chronic pain, and some said their doctors dismissed their symptoms.

“Women don’t know about this, and when they have complications, the doctors act like it is so rare, like they’re so baffled,” Bassan said. “But this is statistically predictable.”

Jennifer Drubin Clark, 42, struggled with pain after her mastectomy in 2018, and it worsened after reconstructive breast surgery in 2019.

But her surgeon seemed to focus only on the appearance of her breast implants, she said.

“I couldn’t play the piano. I wanted to blow-dry my hair, but I couldn’t hold my arm above my head for more than two seconds. I couldn’t hold my kids,” Clark said. “Everything made me cry.”

Pain Often Dismissed

Breast cancer survival rates have steadily increased since the 1980s thanks to improved cancer screening, genetic testing, better treatments, and a rise in mastectomy surgeries.

Post-mastectomy pain syndrome is a consequence of that success, according to recent research papers from anesthesiologists at Baylor University in Texas and surgeons in Chicago and New York. Both papers called for an increased focus on PMPS so that breast cancer patients can not only live longer but live well.

“In the past, when concern was predominantly on patient survival, this pain was often considered acceptable,” plastic surgeons Jonathan Bank and Maureen Beederman wrote in [a 2021 paper](#), adding that mastectomies and other breast surgeries “should be considered truly successful only if patients are pain-free.”

Treatment for post-mastectomy pain has a long way to go, said anesthesiologist Sean Mackey, who leads the pain medicine division at Stanford University. Mackey said this “undertreated”

condition has no consistent definition for diagnosis, no standardized screening, and no treatment approved by the Food and Drug Administration.

Even the name is a misnomer, Mackey said, since the same pain can arise among women who've had other procedures, including lumpectomies and lymph node surgeries.

"The condition was historically dismissed," Mackey said. "Basically women were told: 'You're lucky to be alive. Some pain is expected. Suck it up and deal with it.'"

"That attitude has been slow to change," he said.

Bank, a New York surgeon who [founded a clinic](#) focused on post-mastectomy pain, said the pain is believed to be triggered by nerves that are severed during surgery and then left that way.

The nerves can be sutured back together to minimize pain, Bank said, but most breast surgeons haven't been trained to do this. So it is not surprising, he said, that some patients say their surgeons were dismissive of their pain after mastectomies.

"When doctors don't have an answer or don't know the solution, the easiest thing to do is say there is no problem," Bank said.

PMPS has been documented among cancer patients since the 1970s. Although the condition does not have an official definition, many researchers describe it as frequent pain in the chest, shoulder, arm, or armpit lasting at least three months after surgery.

Mastectomies intended to prevent breast cancer have become more common among women with elevated risks, including genetic mutations and a family history of the disease.

Bassan's grandmother died of breast cancer when she was 40. After her father died of cancer in 2023, a genetic test showed that she was at risk. Grieving and afraid, Bassan sought a preventive mastectomy without hesitation, she said.

Bassan said she was also inspired by actor Angelina Jolie, who disclosed her own preventive mastectomy in a [2013 column](#) in The New York Times. Her account had such a significant impact on rates of genetic testing and preventive mastectomies that medical researchers have studied what they call the "[Angelina Jolie effect](#)."

"I was really swayed by that," Bassan said. "She made it sound, in a way, quite effortless."

The aftermath of Bassan's surgery was far worse than she expected. Using a computer for hours triggered paralyzing pain, so she lost her job and has been out of work for more than a year. Prescription pills dulled the pain but left her in a fog, she said. Desperate, she consulted with multiple doctors until one suggested a nerve stimulation machine, which provided fleeting relief.

About nine months after her mastectomy, a breast reconstruction surgery lessened Bassan's pain,

although she said it still returns in occasional waves. Even though her surgeries were covered by insurance, Bassan estimated her pain has cost her more than \$200,000 in lost wages and drained savings.

“I did not expect to pay this price to have this surgery,” Bassan said. “I don’t know if it was worth it.”

Other women have no real choice.

No ‘Gold Standard’ Solution

Jeni Golomb, 48, was diagnosed with stage 2 cancer in both breasts in 2023 and had a double mastectomy as soon as she could.

Doctors made boilerplate disclosures of possible complications, Golomb said, but she never heard the words “post-mastectomy pain syndrome” until after she had it.

Golomb now manages her chronic pain by taking 1,500 milligrams a day of gabapentin, an anti-seizure drug that can also be used to treat nerve pain. Golomb said she expects to take the drug for years. If she misses a dose, her pain comes roaring back.

“It was the worst pain I ever felt,” Golomb said. “I labored to 10 centimeters, unmedicated, with one of my children, and that was not as bad as this. It was excruciating.”

Gabapentin has proved effective at helping some mastectomy patients with stubborn pain, while others have responded to electrodes implanted in their spinal column, according to [the Baylor study](#), published in 2024.

But that study also said there is “no current gold standard” for how to treat post-mastectomy pain and a scarcity of high-level evidence for what treatments are effective.

Baylor anesthesiologist Krishna Shah, who co-authored the report, said many patients eventually find a helpful treatment, but it often takes “a bit of trial and error” to identify what works for each. And sometimes they never find it.

Susan Dishell, 67, said that after her 2017 mastectomy for breast cancer and reconstruction surgery, she struggled for five years with pain in both shoulders, plus a burning sensation that her medical records identified as nerve pain.

Another surgery swapped out her breast implants to erase her shoulder pain in 2022, Dishell said, but doctors warned her then that her other pain was unlikely to improve.

Since then, she has tried prescription drugs, steroid injections, CBD oil, acupuncture, physical therapy, and chiropractor treatments.

None of it worked, she said, so she stopped trying.

“I have not slept through the night since I’ve had this,” Dishell said. “But it’s OK. It’s not the most terrible price to pay to not have breast cancer.”

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<http://beta.docker.realhealthmag.com/article/women-breasts-removed-thwart-cancer-came-pain>