



## **More Than Numb:** *Women Speak Out on Life After Mastectomy*

Every year, thousands of women undergo mastectomies in the fight against breast cancer<sup>1,2</sup>. While the physical removal of tissue is expected, the total loss of sensation is not. Permanent numbness is more prevalent than you might think. Nerves run throughout the body. They communicate messages to the brain that provide information on your body and surroundings. When nerves are cut or damaged, they can no longer send signals. No signals means no sensation. During mastectomy surgery, nerves are cut and removed with the breast tissue, often leading to permanent numbness<sup>3</sup>. While life-saving or risk-reducing, this procedure can alter a woman's relationship with her body, identity, safety, intimacy, and sense of self.

The absence of feeling in the chest area after surgery is invisible to others but can be devastating for patients. And yet, this impact remains under-acknowledged in clinical settings, care conversations, and survivorship narratives. Some patients are never fully told what sensation loss means—nor how it can affect their daily lives after mastectomy<sup>4</sup>.

The following findings came from a national survey of more than 300 women post-mastectomy, designed to uncover the emotional, psychological, and relational toll of sensation loss.

Source: National survey of 318 women post-mastectomy. All responses are self-reported. The study was conducted by NonFiction Research and funded by Axogen.

# Executive Summary

The research reveals<sup>4</sup>:

## **A profound disconnect from the body:**

87% of women said they experienced numbness or lost the ability to fully feel touch, temperature, or pressure in the breast/chest; 43% describe their chest as feeling “disconnected.”

## **Intimacy and relationships suffer:**

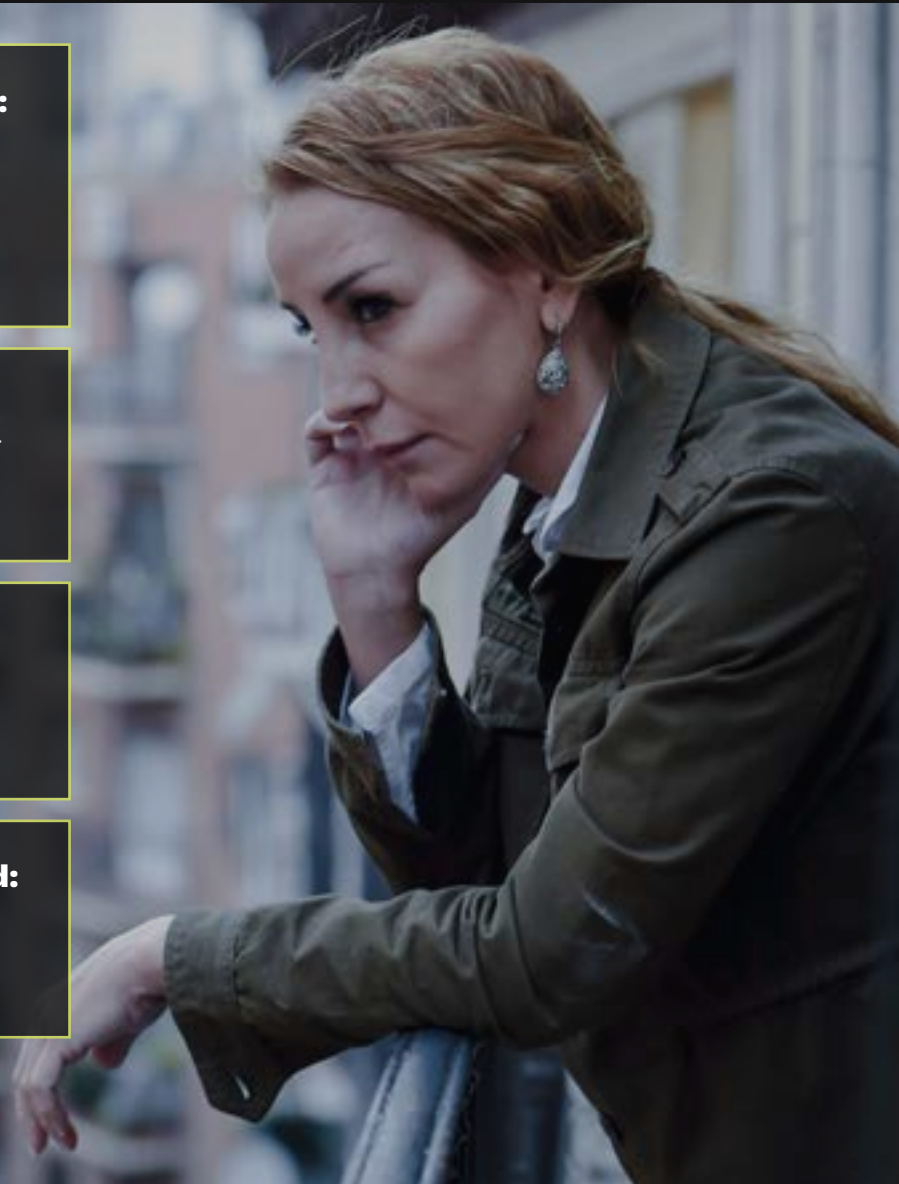
72% say numbness negatively impacted their sex life; divorce or relationship struggles were a common theme.

## **Sensation loss isn't just physical— it's emotional:**

57% say they no longer feel like the woman they once were.

## **Daily life and safety are compromised:**

More than half can't tell when they're touched, and one in four reported injuries or close calls.



These findings point to a critical gap in the current standard of care. Too many women are entering surgery without fully understanding that loss of sensation is a common side effect of mastectomy<sup>4</sup>. This is not a cosmetic issue. It is a question of quality of life, personal agency, and recovery experience.

## **EXPERT INSIGHT**

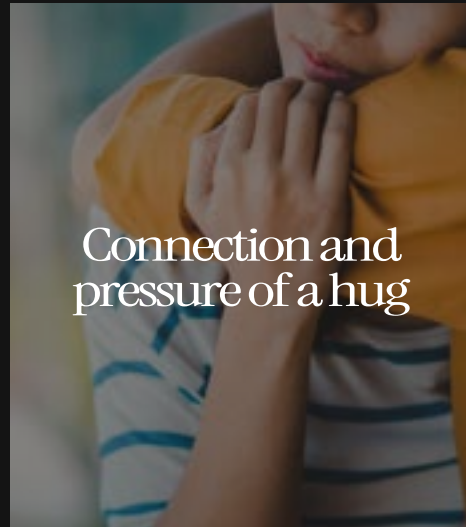
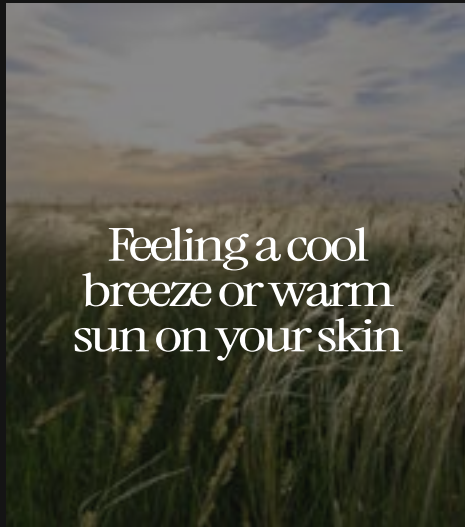
“Surgeons and patients have long understood that the impact of chest numbness after mastectomy goes far beyond the physical implications but haven't had the numbers to prove it. It fundamentally reshapes a woman's experiences after mastectomy. As survival rates climb, the natural next step is to look at life beyond cancer and ensure that the long-term quality-of-life issues are recognized and addressed.

- Dr. Andrea Moreira, plastic surgeon

## What Sensation Really Means

Sensation is more than touch. It's the body's ability to feel warmth, pressure, texture, and pain—signals that help you experience the world and connect with others. During a mastectomy, nerves and breast tissue in the chest are cut and removed. Breast reconstruction procedures are often focused on cosmetic outcomes—recreating the shape, size and look of a breast. As a result, sensation loss is a common and lasting experience for many women after this surgery<sup>4,5</sup>.

Examples of sensations that everyone may experience in their everyday lives<sup>4</sup>:



Without it, the chest can feel numb, disconnected, foreign, or even painful. Many women said they weren't prepared for how deeply this would affect their daily life, relationships, and sense of self<sup>4</sup>.

### EXPERT INSIGHT

“ Too often, women are told they'll 'get used to it,' but numbness is not something easy to adapt to. It changes how women move through the world—how they experience touch, safety, and connection. Sensation is not a luxury. It's a fundamental part of being alive, and the decision to live without it shouldn't be made lightly.

- Emily Hansen, Senior Director, Axogen

# Profound Disconnect from the Body

After a mastectomy, many women experience a loss of physical connection to their bodies. This goes beyond numbness—it’s a fundamental disruption in how they perceive, inhabit, and relate to themselves. Respondents described their chests as feeling “foreign,” “disconnected,” or “not mine anymore.” For some, this disconnect led to self-consciousness, grief, and even self-hate. Though invisible to others, the loss of sensation can fracture a woman’s relationship with her own body and with the person she once was<sup>4</sup>.

Women use a variety of language to describe what the loss of sensation really feels like<sup>4</sup>:

Said they feel numb	69%
Their breasts no longer feel like theirs	46%
They no longer feel like the woman they once were	57%
They feel like their body is no longer their own	40%
Report pain or shooting in the chest area	30%
Experienced self-hate related to numbness	27%
Said numbness makes them feel “deeply disconnected”	43%
Said it impacts their ability to feel “normal” again	54%

“

It feels like it’s not attached to me. It feels like my brain does not want to comprehend that part of my body anymore.

- Survey respondent, FL

“

I’m a shell of the woman I once was. I feel like I’m trapped in someone else’s body because I can’t feel anything but numbness and pain.

- Survey respondent, MA

“

It makes me feel disconnected from my own body and like I’m a stranger in my own skin. It makes me feel like less than a human and less like a woman.

- Survey respondent, TX



## EXPERT INSIGHT

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I’ve taken care of many patients who describe a major disruption in how they experience their bodies after mastectomy. They describe feeling like they no longer inhabit the space where their breasts once were. That disconnect can impact everything from self-confidence to intimacy. For many, it doesn’t fade with time. It becomes a new kind of silence they’re expected to live with.

- Dr. Warren Ellsworth IV, plastic surgeon

# Underestimation of Sensation Loss Before Surgery

It's difficult to understand the absence of something you've never consciously noticed, especially while facing the fear and urgency of a cancer diagnosis. In that moment, survival understandably takes precedence, and many women go into surgery without a complete appreciation of what sensation loss actually means—or that it could be permanent. While most are told they will experience numbness, the majority did not comprehend the depth or permanence of what they are losing: the ability to feel their own skin, to register warmth, pressure, or connection. Nearly half of respondents said they underestimated the impact of sensation loss.<sup>4</sup> This gap in awareness leaves women feeling misled, unprepared, and in some cases, betrayed. The emotional fallout is often worse than the physical, with many women expressing regret over decisions they made without the full picture.<sup>4</sup>

“

Not all doctors warn you or prepare you for the outcome or symptoms. I wish I had because nobody told me anything about what I'd feel like afterwards.

- Survey respondent, MA

“

I wish someone would've gone out of their way to make sure I truly understood what was going to happen to me to make the reality of this new life more realistic because no one prepares you properly for what to expect.

- Survey respondent, TX

“

I wish they understood it is not just a physical loss but also emotional and psychological. It feels like losing your identity and makes one feel lifeless.

- Survey respondent, GA

Said they were told they'd lose sensation <sup>4</sup>	75%	Understood what that meant <sup>4</sup>	47%
Underestimated the impact of sensation loss <sup>4</sup>			45%
Did not remember being told anything about sensation loss <sup>4</sup>			17%
Did not understand it at all <sup>4</sup>			15%

## EXPERT INSIGHT

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Most women go into mastectomy surgery focused solely on survival, and rightly so. However, they do not realize that losing sensation is the norm, not the exception. When they wake up numb and it doesn't go away, it's not just a surprise; it's a betrayal of their expectations for what a fully reconstructed breast means. We owe it to patients to prepare them honestly—not just for the risks of surgery, but for what life in a numb body might feel like.

- Dr. Lisa Hunsicker, plastic surgeon



“ Intimacy just doesn't feel the same; I've lost all desire there.

- Survey respondent, WI

## Sensation Loss Disrupts Intimacy and Relationships

Sensation loss after mastectomy doesn't just affect the body. It affects connection. For many women, numbness in the chest deeply impacts physical and emotional intimacy, often in ways they didn't anticipate. More than two-thirds of respondents said their sex life was negatively affected, with some sharing that they could no longer feel their partner's touch or had to pretend during intimacy to maintain their relationship. But the loss extends beyond romantic partners. Women reported feeling disconnected from children, friends, and family—describing a painful emotional gap where touch used to bring closeness. In some cases, the strain led to relationship breakdowns, with women expressing a sense of isolation, grief, and guilt over something they had no control over<sup>4</sup>.

Said numbness negatively impacted their sex life <sup>4</sup>	72%
Lost the ability to feel intimate touch <sup>4</sup>	56%
Said sensation loss reduced their sex life satisfaction <sup>4</sup>	55%



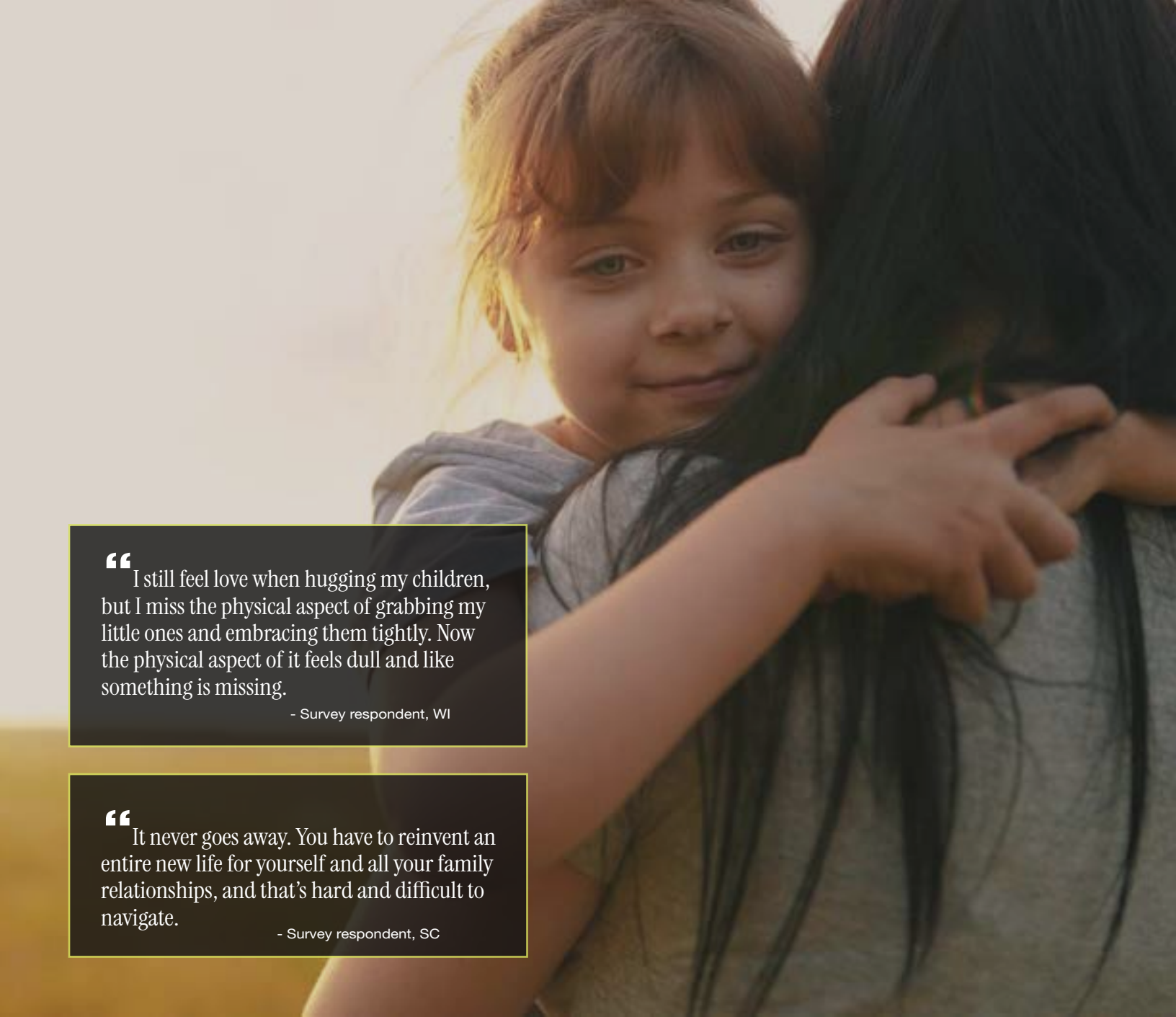
**Many respondents reported strain on romantic relationships or even divorce<sup>4</sup>**

“ It was a big impact on my intimate experiences like my sex life and relationships. With my partner, it was a horrible experience, and it made me more depressed. I felt pressure and I pretended to like it.

- Survey respondent, NY

“ I feel like something is missing. A void now exists for me. A void that feeling normal before this happened to me once filled. My relationship with my husband has suffered greatly. I lack confidence, and I don't feel attractive.

- Survey respondent, KY



“ I still feel love when hugging my children, but I miss the physical aspect of grabbing my little ones and embracing them tightly. Now the physical aspect of it feels dull and like something is missing.

- Survey respondent, WI

“ It never goes away. You have to reinvent an entire new life for yourself and all your family relationships, and that's hard and difficult to navigate.

- Survey respondent, SC

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Said their relationships were impacted<sup>4</sup>

33%

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Said they miss the warmth of a hug<sup>4</sup>

47%

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Said sensation loss affects how they connect with their children<sup>4</sup>

18%

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#### EXPERT INSIGHT

“ Sensation loss after mastectomy doesn't just affect the chest. It affects connection, confidence, and intimacy. I've had patients tell me they feel invisible in their relationships. This isn't about vanity. It's about recognizing how deeply numbness can affect closeness and quality of life.

- Dr. Kristin Rojas, breast surgical oncologist and gynecologic surgeon

# The Emotional and Mental Toll of Numbness

The psychological impact of sensation loss is profound and persistent. Many women described their post-mastectomy experience as a form of grief, not just for their breasts, but for the part of themselves that could feel. Numbness becomes a daily reminder of what's missing. Some said they felt depressed, anxious, and even had suicidal thoughts. Nearly half of respondents said the loss is always on their mind. The absence of sensation doesn't just affect physical comfort—it erodes confidence, self-worth, and the ability to feel like a whole person. While physical healing may progress, the emotional recovery often stalls in silence<sup>4</sup>.

**58%** felt sadness or depression<sup>4</sup>

**41%** reported grief<sup>4</sup>

**40%** reported disappointment<sup>4</sup>

**31%** reported resentment<sup>4</sup>

“

It was the emotional whiplash of expecting warmth and meeting void. Running my fingers over my chest and feeling nothing.

- Survey respondent, VA

**46%** said the numbness is always a weight on their mind<sup>4</sup>

**26%** said they feel mentally foggy<sup>4</sup>

**31%** said they feel “mutilated”<sup>4</sup>

“

I don't feel like the person I used to be, and even worse, I don't feel like I'm even human anymore. I feel like I'm unrecognizable, and I grieve the loss of the person I used to be.

- Survey respondent, TX

“

I was very depressed. I did not look or feel like a woman anymore. I'm still coping until this day.

- Survey respondent, MN

“

This isn't my body. All I feel is pain and the sensation of my foot falling asleep, but instead of it being my feet, it's my entire chest.

- Survey respondent, MA

“

I'm clinically depressed, I get dressed in the dark, I hardly leave home, and work remotely as often as possible.

- Survey respondent, MA

Said they've reached acceptance—but only after significant emotional processing<sup>4</sup>

25%

Reported anxiety about how their body responds to touch<sup>4</sup>

46%

Said numbness has impacted their desire to live<sup>4</sup>

18%

## EXPERT INSIGHT

“ When women describe feeling numb after a mastectomy, they're often talking about more than just physical sensation. It's a psychological numbness too—a disconnection from the body that can lead to grief, anxiety, and identity loss. The trauma doesn't end with the surgery. For many, it's just beginning.

- Dr. Kristen Casey, clinical psychologist

## Impacts on Everyday Life

Sensation loss isn't just about emotions or intimacy—it's a safety and quality-of-life issue. Many respondents reported difficulty performing basic daily tasks, from shaving and dressing to exercising and sleeping. More than half can't tell when they're touched, and a quarter have experienced injuries or close calls due to their numbness. The loss of sensory feedback creates a "blind spot" on the body, making once-routine activities physically awkward, uncomfortable, or even dangerous. For some, this leads to constant self-monitoring, wardrobe changes, loss of confidence at work, and sleep disruption. What seems like a small loss from the outside has daily, compounding consequences for those living with it<sup>4</sup>.

27%

said numbness affects basic daily activities<sup>4</sup>



44%

couldn't tell if their bra is too tight or the underwire is poking them<sup>4</sup>

“

How I feel about myself has changed a lot. I used to be very outgoing, a social butterfly. Now, I don't go anywhere. I get mad at myself because I am letting life pass me by, but I can't pull myself out of this deep, sad cycle.

- Survey respondent, NY



31%

said they miss the comfort of a pet lying against their chest<sup>4</sup>



55%

said they can't tell when someone touches them<sup>4</sup>

# 25%

experienced an injury or close call (e.g., burns, cuts, sunburns)<sup>4</sup>

“

I was severely sunburned because I didn't feel the burning sensation or temperature of the hot sun when I tried to go to the beach. I felt so stupid for even trying to do something normal.

- Survey respondent, FL

“

I was in the backseat of a friend's car and their lit cigarette came back into my window when she threw it out and it landed on my chest. I didn't realize it till the smell of burnt skin and fabric started to rise. I had a third degree burn on one of my breasts and the shirt I was wearing had a burn hole in it.

- Survey respondent, OH

# 28%

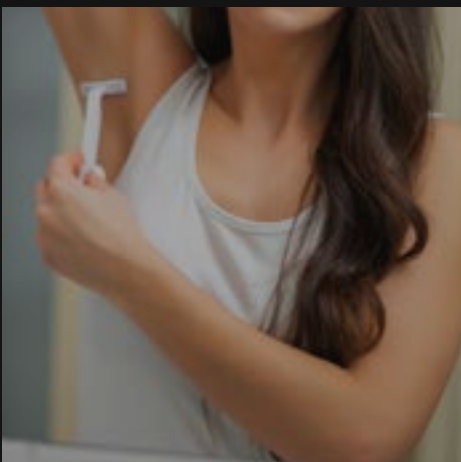
said numbness impacts their sense of safety in the car (e.g., seatbelt)<sup>4</sup>

# 31%

said they can't safely shave their armpits<sup>4</sup>

# 26%

said they can't tell if they are overextending during exercise<sup>4</sup>



“

I ran into a door and thought it wasn't a big deal until I looked down and my implant had deflated. I had to get corrective surgery. That's how easy it was not to notice severe traumatic impact.

- Survey respondent, Washington DC

35%

said it impacts their sleep<sup>4</sup>



50%

said they miss the feeling of fabric or clothing on their skin<sup>4</sup>



43%

said they struggle to carry things in the same way<sup>4</sup>

“

I definitely feel like the clothes that I used to love to wear, I don't anymore. It just doesn't feel like I'm myself, and I've never been insecure.

- Survey respondent, MI

20%

said it affects their performance or confidence at work<sup>4</sup>



45%

said they miss the ability to feel warmth or coolness<sup>4</sup>

#### EXPERT INSIGHT

“ Most people don't realize that sensation is how we connect with the world and how we stay safe. When it's gone, basic things change in ways no one prepares you for. Without sensation, they have to actively think about avoiding injuries, struggle to find comfortable sleep positions, and worry whether it's safe to exercise. It's a constant reminder that their bodies no longer work the way they used to.

- Dr. Jonathan Bank, plastic surgeon

““

Most people assume you go back to a normal life after a mastectomy and then reconstruction surgery. They just don't understand that this numb feeling never goes away.

- Survey respondent, TN

““

The physical scars have healed, but it's not the same. I am not the same.

- Survey respondent, MA

““

Some may think it's just numbness, get over it. They should realize that it's not just a numb breast. It's the loss of your womanhood. It's the loss of your feminine feeling.

- Survey respondent, NY

## Invisibility and Isolation

One of the most painful aspects of sensation loss is how invisible it is to others. Unlike scars or fatigue, numbness can't be seen, and many women feel like they're carrying a private grief that no one acknowledges. Cultural expectations to be grateful for survival often silence conversations about what's been lost. As a result, many women don't speak up about how much the numbness affects them, fearing they'll seem ungrateful, burdensome, or overly sensitive. The emotional weight of this silence—combined with the lack of understanding even within survivorship spaces—leaves many feeling unseen, isolated, and alone in their experience<sup>4</sup>.

Said they struggle to express what numbness feels like <sup>4</sup>	67%
Said they've stayed silent because they feel they should "just be grateful" <sup>4</sup>	54%
Said it's too painful to admit how much the loss mattered <sup>4</sup>	50%
Said cancer is an uncomfortable topic and hard to revisit <sup>4</sup>	48%
Said others expect them to have "moved on" <sup>4</sup>	36%
Said expressing their feelings feels like a burden on others <sup>4</sup>	43%
Said they didn't have anyone to talk to <sup>4</sup>	30%

### EXPERT INSIGHT

““ We talk a lot about survival after breast cancer but not enough about what it means to live in your body afterward. Sensation loss is invisible to others, but it's something women carry in silence, often feeling like they shouldn't complain.

- Dr. Anne Peled, breast and plastic surgeon

## Desperate Desire for Sensation

The data is clear: women describe numbness as more than an inconvenience—it’s dehumanizing. The absence of sensation erodes comfort, confidence, connection, and normalcy. Women wished they’d had more information before surgery, underscoring how critical it is to name the loss out loud. This is not about vanity. It is about recognizing the profound impact sensation loss can have on quality of life<sup>4</sup>.

Survey respondents described the profound impact of sensation loss, saying they would be willing to give up deeply personal things if it meant avoiding the experience of numbness<sup>4</sup>:

Said they would rather isolate for a year than live with numbness	22%
Said they would rather give up sex for a year than live with numbness	39%
Said they would rather lose their hair permanently than lose sensation	17%
Said they would rather sacrifice a different limb than lose sensation	14%
Said they felt powerless, saying they would do “almost anything” to avoid the ongoing numbness	16%

“ I don’t feel normal because I can’t date, I can’t go out to the beach, I can’t do anything I used to do normally freely.

- Survey respondent, FL

“ It might seem like a minor side effect of having a mastectomy, like you might brush it off beforehand.

- Survey respondent, WI

“ I wouldn’t wish this on my worst enemy. I hope nobody ever has to feel this. It’s very saddening.

- Survey respondent, MS



### EXPERT INSIGHT

“ Survival is the primary goal of breast cancer treatment, but patients deserve to thrive, not just survive. Women are often told to be grateful for being alive, which can leave them feeling unseen as they struggle with the lasting effects of numbness. Patients can become emotional when this struggle is finally acknowledged. It’s not an emotion of distress, but one of deep validation—the profound feeling of being seen for who they are, beyond their cancer journey.

- Dr. David Weintritt, breast surgeon

## Words of Advice and Empowerment

The women who participated in this research didn't just share what they lost—they shared what they've learned. Many spoke directly to those who may be facing a mastectomy, offering raw, honest, and hopeful reflections. Their collective wisdom reinforces what no clinical pamphlet can fully capture: the need for self-advocacy, emotional support, and grace through a difficult and deeply personal journey.

### **Ask questions. Do your research. Advocate for yourself.**

Respondents said they wish they had known more before surgery, not just about the physical side effects but also about what sensation loss would really mean.

“ Ask more questions and make sure your concerns are addressed before your surgery.

“ I would encourage people to find a surgeon who listens to them. I wish someone would've gone out of their way to make sure I truly understood what was going to happen to me.

### **You are not alone.**

Many women expressed a desire to support others because of their own negative or painful experiences, noting how isolating they can be if they don't have the right people or resources around them.

“ We will always be human no matter what. We can feel emotions, and that's okay. Please don't get down on yourself. You're not a monster.

“ There's no fix-all advice. But know that you're not alone and there are a lot of us out there, and we want to love you back to life when you feel like you can't go on.

“ [We need] more of a support group. We need each other, not just in the sense of dealing with a scary situation, but as women as a whole



### **Be kind to yourself. This is not easy.**

Respondents spoke about the emotional toll of recovery physically, mentally, sexually, and spiritually. Many emphasized the importance of self-compassion and patience.

““ Don't be afraid to grieve. You are not just losing tissue —you're losing a part of how you experience life.

““ Nothing can ever fully prepare you. But you can get through this.

““ You are not ungrateful for surviving just because you feel the loss.

### **Healing takes time. But it will come.**

Others shared realistic but hopeful encouragement about what life looks like on the other side of mastectomy.

““ You'll miss the old sensations, but over time you may find new ways to connect with your body.

““ It's going to make you sad for a while, but it won't be sadness forever.

““ Don't let this get you down. There's always more life to live. And never give up.



## Final Reflections

The women who shared their experiences in this study did more than answer survey questions—they illuminated an often-overlooked reality of life after mastectomy. Their stories and responses reveal a clear pattern: sensation loss is not a small or temporary side effect. It is a deeply felt absence that can reshape identity, relationships, safety, and emotional well-being.

While mastectomy may be necessary to save lives, the experiences shared here suggest that not enough is being done to prepare women for what comes beyond survivorship or to support them in coping with the lasting impact of sensation loss. These findings highlight the need for better conversations, clearer expectations, and greater understanding of the full impact of chest numbness.

This report is a step toward making those conversations possible. It exists to give voice to what many have felt but few have said and to offer a deeper, more complete picture of recovery.

### EXPERT INSIGHT

“As surgeons, we must look beyond the operating room. Our work doesn’t end with a healed wound—it continues as our patients navigate the realities of life after mastectomy. Survival is only the first step. We have a responsibility to acknowledge how physical changes like sensation loss can shape emotional, functional, and everyday experiences long after recovery.

- Dr. Alex Mesbahi, plastic surgeon

# Methodology

This report is based on a national survey conducted in March 2025 using the market research platform Opinion Route. The survey gathered responses from 318 women who underwent a mastectomy within the last 10 years. Respondents represented a diverse range of surgical experiences, including various types of mastectomy and reconstruction, as well as individuals who opted not to undergo breast reconstruction.

Participants were sourced using known sampling methods. Respondent identities were verified through industry-standard fraud prevention techniques to ensure data quality and response integrity.

The survey achieved a 95% confidence level with a 5.5% margin of error based on an estimated 1 million Americans who have had a mastectomy over the past decade.

All participant responses were anonymized and reviewed for seriousness and completeness. Survey findings reflect subjective patient-reported experiences and perceptions. This survey was exploratory market research and was not designed to establish clinical, psychiatric, or causal conclusions. The survey did not include a control group or validated mental health assessment tools. Where open-ended responses are quoted in this report, they are used with permission and may have been lightly edited for clarity.

If you or someone you know is experiencing emotional distress or thoughts of self-harm, support is available. Call or text 988 to reach the Suicide & Crisis Lifeline.

## About

This research was supported by Axogen, Inc., in partnership with Nonfiction Research.

### About Axogen

Axogen is a medical technology company dedicated to advancing the science of peripheral nerve care. Axogen supported this survey in partnership with Nonfiction Research to help better understand patient perspectives on life after mastectomy.

### About Nonfiction Research

Nonfiction is a research company focused on uncovering the deeper, often unspoken thoughts and emotions that influence human behavior. Through a blend of qualitative and quantitative methods, they help organizations better understand the people they serve. Nonfiction's work spans various topics—from financial stress to cultural identity—and has informed campaigns, media strategies, and product development for some of the world's most innovative brands.

**References:** **1.** United States Census Bureau. Sex by age. 2013. Accessed September 10, 2025. <https://data.census.gov/table?q=B01001&y=2013> ; **2.** Steiner CA, Weiss AJ, Barrett ML, Fingar KR, Davis PH. Trends in bilateral and unilateral mastectomies in hospital inpatient and ambulatory settings, 2005–2013. HCUP Statistical Brief No. 201. Rockville, MD: Agency for Healthcare Research and Quality. Accessed August 19, 2025. <https://hcup-us.ahrq.gov/reports/statbriefs/sb201-Mastectomies-Inpatient-Outpatient.jsp>; **3.** Hamilton KL, Kania KE, Spiegel AJ. Post-mastectomy sensory recovery and restoration. *Gland Surg.* 2021;10(1):494–497. doi:10.21037/gs.2020.03.22; **4.** Axogen/Nonfiction Research, national survey of 318 women post-mastectomy, March 2025. **5.** Flowers K, et al. Pain, numbness, or both? Distinguishing the longitudinal course and predictors of positive, painful neuropathic features vs numbness after breast cancer surgery. *PAIN Reports.* 2021;6(4):e976. doi:10.1097/PR9.0000000000000976

Respondent quotes are from a 2025 national survey of women post-mastectomy, conducted by Nonfiction Research in conjunction with Axogen, Inc. This information is provided for educational purposes and is not intended to promote or endorse any treatment or product.

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