

# Fit and Comfort



POST-MASTECTOMY FITTERS GO BEYOND MEETING PHYSICAL NEEDS TO ALSO SOLVING EMOTIONAL AND FINANCIAL ISSUES

**A**fter years of working to fit mastectomy patients with prosthetics and apparel, consultant Constance Niclas, CMF, CF-M, says she knows the single-biggest mistake others in the business make—even before they open their doors for the first time.

“A lot of them do this out of compassion. They think they’ll love doing this because they’re survivors themselves. But it can’t be a hobby. It has to be a business,” Niclas advises.

Maintaining a professional focus is necessary for a multitude of reasons, she says. Breast forms and post-surgery bras are not fast-selling items. The fit is individualized, so product lines have to be extensive and varied to give customers plenty of choices. Securing payment for these products from insurers and Medicare, especially when each woman requires a customized fit, can be especially challenging.

Certainly, working with patients in any specialty of orthotics and prosthetics can be emotionally difficult. But those who fit breast cancer patients with post-mastectomy forms and devices say their jobs require special care and compassion to help women who’ve just lost one or both breasts. Practitioners contend that success in this field requires the right balance of technical expertise, emotional sensitivity, and mastery of the insurance and reimbursement process.

## Grief—and Relief

Amber McCann, a certified bra and mastectomy fitter at A Woman’s Place on Main Street in Laurel, Maryland, says she was surprised by the emotional requirements of her new specialty when she decided to expand her business from breastfeeding supplies to mastectomy products about a year ago. With that decision,

she became a fitter and counselor, saying that it’s a role that not everyone can take on.

“Some of the people we hired became very nervous and uncomfortable in the counseling role we take on,” she says. “They were qualified, but they couldn’t do that part of it and they didn’t work out.”

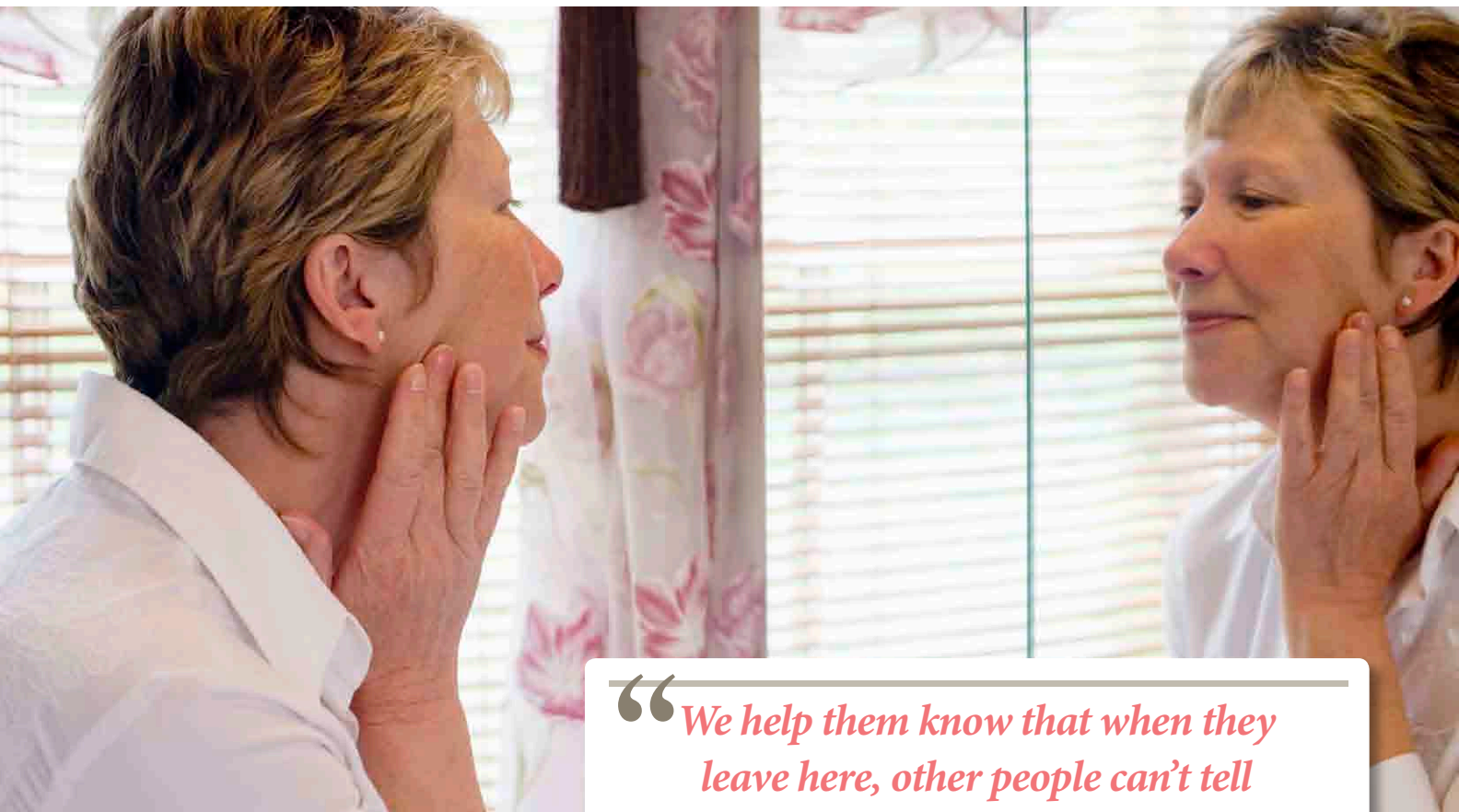
McCann’s shop, which is furnished like the living room of a luxury home, provides plenty of boxes of tissues, alongside bras and prosthetics. Customers often get emotional both from the trauma of breast loss and from the relief that they can be fitted with the right form.

“You still play cheerleader, even when someone is years out of surgery,” she says. “It’s not unusual at all to have tears in here.”

Nina Miller, CMF, Snell Prosthetic and Orthotic Lab, Little Rock, Arkansas, agrees. “These women are not just dealing with the loss of part



BY KIM FERNANDEZ



*“We help them know that when they leave here, other people can’t tell they’ve had breast cancer.”*

—Nina Miller, CMF

of their body,” she says. “They’ve lost something very emotionally important to them that makes them feel whole. What we do is make them feel better. We help them know that when they leave here, other people can’t tell they’ve had breast cancer. They look just like everybody else, and that’s really important to them.”

### Challenges and Changes

Post-mastectomy prosthetics have undergone dramatic changes over the last 10 years. For one, they’re much lighter than they were even five years ago. Manufacturers now realize that lighter is better to ensure greater comfort and wearability for women.

That’s a change from early products that tried to simulate natural breast weight in order to balance the body. Now, forms are made as light as possible, and users approve.

While product improvements are beneficial to customers, shop owners and fitters are faced with the challenge of how to recommend the right

prosthetics—and ensure that products get sold, and that their business is profitable.

“You need a framework to understand the pricing of the products,” says Niclas. Mastectomy boutique owners can quickly become overloaded with products. “It’s not a quick-turn business, and you can easily end up with storage issues,” she suggests.

Understanding the features and benefits of products is critical, and so is knowing what prosthetics insurance will cover. “I have to know: Should I put a woman into a swimming form? Would she be better off if we gave her a shell? And you have to understand the insurance regulations of what you’re selling. If I have a choice of putting a woman into a shell that costs \$230, or a swim prosthetic which is bulkier but cheaper, those are issues

a shop needs to understand. What’s going to drive business back?”

You have to know the products, agrees Angela Sombrano, CMF and office manager for Scope Orthotics & Prosthetics in Torrance, California. “A lot of people think women have to buy a bra anyway, so what’s the difference? But a lot of manufacturers are just too expensive and insurance won’t pay,” she warns.

When insurers balk, customers must either decide to pay the difference for a product upgrade, or purchase a different product that meets insurers’ requirements. Sombrano says she’s seen a shift in what customers are willing to pay for, and they’re being more selective. “Most patients now don’t want to pay for the upgrades,” she says. “Years ago, they did. But with this economy, they’re not doing it.”

“*Customers need to realize that bras, like cars, require maintenance and are not designed to last a lifetime.*”

—Constance Niclas, CME, CF-M

Recognizing this shift, Sombrano now asks customers if they want to see products only covered by insurance, or if they're willing to pay some out-of-pocket costs for upgraded prosthetics.

“I'll show a patient the style of bra their insurance will pay for,” she says. “If they say they're willing to pay, I'll show them everything.” But, because upgraded bras can be prettier and more stylish, she says, it can be too difficult for women to see them and then be told their insurance won't cover them.

Unfortunately, Niclas says, not all shops can keep extra merchandise on hand, so customers sometimes must have products ordered without having tried them on. And because these products are expensive and not quick sellers, many shops maintain a no-return policy. Some customers find they're stuck with a bra that looked good on paper, but now simply doesn't fit right.

“People don't have money to spend like they used to,” she says. “Breast cancer rates increase with age, and you get a lot of elderly women who don't want to spend \$300 this year on something, even though Medicare will reimburse them.” Customers who go online to buy cheaper products can end up with ill-fitting prosthetics that make them feel even more self-conscious.

### Knowing the Limits

Niclas says it's vital for mastectomy shops and boutiques to ensure that staff members are trained and certified in fitting. They also need to

know that different products fit differently, and that ordering various items in one size won't result in the same fit on a real body.

“It comes down to knowing the customer's body” and advising her that as she ages, her product needs will change, says Niclas. “It's a good idea to keep a birthday list and get in touch with customers on their birthdays. Let them know that it's been two years since they've been in, and Medicare will allow them to come in for a fitting.” Customers need to realize that bras, like cars, require maintenance, and are not designed to last a lifetime, says Niclas.

“I'm a firm believer in fitting them into something that looks good on them,” says Sombrano. “Not every style looks good on every woman, and not every form looks good on every woman.”

Niclas also advises checking in with customers a week or two after their fittings to see if they'd like their fitting rechecked, and if they're satisfied with their purchase.

“The insurance companies don't like us to keep up with patients,” admits Sombrano. “They don't like us to send reminder notices.” But she says that women should be buying a new bra every year.

Insurers and Medicare typically allow mastectomy patients to purchase two bras every year, and one form every two years. These restrictions often make women overly anxious about choosing new products because they worry about being stuck with a bad choice. Women who don't have insurance and don't qualify for Medicare often cannot afford prostheses. “These women are without anything and have a hard time finding the means to pay for any prosthesis,” says Miller.

The latest challenge, she says, has resulted from the move toward providing reconstructive surgery during mastectomy procedures. While older women tend to pass on the procedure, many young women do take advantage of this option, but are surprised when the results aren't totally perfect.

“I see patients afterwards who come in because the reconstruction isn't perfect,” she says. Fitting these women with prosthetics to remedy the imperfect reconstruction is sometimes much more complex than fitting a patient with a total breast form. “Maybe 5 to 8 percent of my patients have had reconstructive procedures that aren't good,” she says.



## Custom Devices

While most fitters say that off-the-shelf forms fit most women, there are some who have had such radical surgery that custom devices are needed. These women also must often face months of battling with their insurers, which can be both exhausting and emotionally draining. And the fitters are often in the midst of these difficulties.

"Twenty-five percent of our women have damage to muscles in their backs or sides, and they need a custom item so they can even walk, and do normal things, without a lot of pain," says Miller. "And insurance companies just won't pay for it."

Rick Fleetwood, CEO, Snell Prosthetic and Orthotic Lab, acknowledges the major difficulties many of these women face to get custom-fabricated prostheses. "You have to jump through hoops and just do unbelievable things to get that prosthesis.

It's almost impossible. And it seems just not fair." It's "unbelievable," he says, that women who've endured breast loss and who need a prosthesis cannot get a product that's the exact right fit. "It's a lack of understanding or a lack of education," he says. "There's a huge heightened awareness about breast cancer itself. But when it comes to custom-fabricated devices, there's this huge black hole. Nobody understands why it's not done, and why it's not okay."

Fleetwood says that the prosthetics industry needs to be vigilant about other practices to effectively serve breast cancer patients. For instance, he says that his company mandates that only women fitters work with mastectomy patients.

"Part of our corporate philosophy is to make sure that women are talking to women in this situation," he says. "Normally, we don't do that. But in this particular situa-

tion, we find it's imperative that we have women taking care of women."


Other fitters say they, too, believe that in this one segment of the industry, special rules should apply. "It's a big issue," says Sombrano. "I ask my women, and they say they don't want a man putting them back into a womanly figure. Years ago, there were quite a few men who used to do fittings. In the past 10 years, I haven't seen a man out there doing it anymore."

Miller says her shop also recruits female volunteers—former cancer patients—to help mentor new patients as they go through their first fittings.

"Some of the volunteers may have been patients of ours," she says. "They mentor women who are going through it now because they're not just losing their breast. They're facing chemotherapy or radiation, and they're facing a whole lot of emotion."

McCann agrees. "Another woman is going to have a unique perspective," she says. "I don't want to sound discriminatory, but I don't think a man can fully comprehend the part of our identity that's wrapped up in our breasts. I think having another woman working with them is terribly important."

She says that a supportive viewpoint matters in every part of her job, starting when customers walk through the door.

"A woman came in fresh from surgery and said she was scared to hug anyone because she didn't want them to feel that she was different," she says. "I hugged her, and I could assure her that I didn't feel anything different. That's nothing I planned when I got into this business. But we certainly play that role." 

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