

... (Paul Desmarais/Staff photo)



Comfort in the bag

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Gift helps mastectomy patients cope after surgery

Maureen Lutz often speaks of the "crushing moments" that followed her 2005 mastectomy at Stamford Hospital. The surgery was bad enough. "Losing my breast was devastating. My body was so traumatized," she says. "But for me it was the little unexpected things that came afterwards that were the real emotional killers."

Her lips were chapped. Her mouth was dry and she craved sweets, but couldn't really eat anything. Her post-surgical drains hung awkwardly on her body, making it difficult to shower. Her feet were so swollen she couldn't get her shoes on when it was time to leave the hospital. And then there was the car ride back home to Ridgefield.

"I put the seat belt on and I was in agony having that thing strapped across my chest. I remember just groaning the whole way home." Nursed at home by her sister, Patty, Lutz began jotting down the things she wished she had known before her operation. "I think my sister thought I would write a book, because that's me, I'm a doer. So every time I complained or had an idea she said, "Write it down." But instead," she says, lifting a tote bag stuffed with goodies for other mastectomy cancer patients, "I did this."

"This" is the Necessities Bag, a smart tote stuffed with items meant to ease the burdens of women recovering from mastectomy during their hospital stay and in the first few days home after surgery. Since Lutz founded her Ridgefield-based organization, just weeks after her March 2005 operation, her cottage charity has distributed more than 1,000 bags to mastectomy patients at Stamford, Greenwich, Norwalk and Bridgeport hospitals and beyond. Married, and expecting a grandchild, for years she worked in development jobs for charities and nonprofits. "I think I was meant to do this. I often say that breast cancer helped me refine my purpose in life."

On average, 35 to 40 bags are distributed in Fairfield County each month, and as many as 70 bags statewide through its upstate affiliate. Each bag is stuffed with more than a dozen items Lutz wished she had packed for her own mastectomy. At all of the area's major hospitals, breast cancer surgeons and nurse coordinators have a supply of the bags, to be given to women in the days before they check into the hospital for surgery. "This is meant to start a very personal discussion between the patient and her caregivers

about the days to come," says Lutz, who constantly lauds the local doctors and nurses who hand out her bags.

At a recent luncheon, the Necessities Bag team celebrated several of those caregivers including Jan Larkin, nurse coordinator at The Breast Cancer Center at Greenwich Hospital; Diane Lizio, surgical nurse at the Aesthetic Surgery Center of Darien, Michele Speer, nurse coordinator of the Women's Breast Center at Stamford Hospital; and Nancy Sokolowski, breast health specialist at the Smilow Family Breast Health Center at Norwalk Hospital. Inside each bag, items range from plain lip balm and fruity LifeSavers to men's T-shirts with roomy arm holes; soft, oversized bandages; and small, cushy pillows sewn in cheery fabrics to slip under the arm or seat belt for comfort. The pillows are made by a small army of church-based sewing groups, some of the charity's most cherished volunteers.

"After a mastectomy, the area under your arms can really kill, especially if you've had lymph nodes removed," explains Lutz. "A small pillow is just right." Also included in every bag are several yards of cut ribbon, which can be used to neatly tie up hanging drains during a much-needed shower. "When I first tried to shower, I was just baffled about my drains," says Lutz, who encloses several small notes in her bag explaining the intended use of each item.

"Just the right amount of ribbon and you can have that shower that is going to make you feel human again." Each bag costs about \$50 retail to assemble; most are paid for by foundations or private donors. Lutz is as particular about what doesn't go in the bags as she is about what does, notes Lisa Turnick of Fairfield, who works on the Necessities Bag staff as a Connecticut distribution coordinator. Items that might be handed out in hospital, such as robes, shampoo and toothpaste, are not replicated. Lutz refuses donations she deems too promotional or unnecessary. "Someone who has just had their breast removed doesn't need a pen with a drug company name on it," says Lutz. She also refuses to let anything with the color pink - including ribbons - enter her bags, notes the charity's lead volunteer, Mary Collins of Westport.

"If there is a hint of pink on the pillow fabric, she isn't happy," Collins says. "Sometimes we have to twist her arm and say, 'Maureen it's not a lot of pink.'" Lutz's distaste for the color long associated with breast charities and survivors is palpable. While she heralds the accomplishments of the pink movement, particularly in the areas of research, she says: "I don't do pink because I want these women to have privacy. You walk around with something stamped with a pink ribbon and right away, you're outed. My bag is lovely, but it is discreet. It tells no one what they've just been through. Some women choose to be very open about this, like me. Some are very private. They should decide if they want things with pink ribbons on them. Not me."

Lutz has become a spokesperson on issues related to mastectomy recovery, including an appearance on ABC's "The View" last year to discuss her project. The Ford Foundation is underwriting a national media tour for her to promote the charity this month, Breast Cancer Awareness month. Her hope is to encourage more interest in starting affiliates of her charity at hospitals around the country. Already such organizations have been formed in New York, New Jersey, California, Illinois, Colorado and Texas. "I wish I didn't have to hand out any bags, but as long as women are having mastectomies, this is what I feel called to do," she says.