

Lymphedema: The Lemonade of My Life

Design and Development Coordinator
National Lymphedema Network
By Robin Miller

The Lemons

In March 2005 I was diagnosed with Stage III breast cancer at the age of 21. Because I was young and my tumor was large and already spreading to my lymph nodes, I was treated very aggressively. I underwent chemotherapy, bilateral mastectomies, multiple reconstructive surgeries, and radiation. To get all the cancer cells, my doctors also removed a large cluster of lymph nodes from my armpit.

I sincerely hoped that once I was finished with radiation, I would be able to go back to a somewhat “normal” life. Unfortunately, shortly after I finished treatment I developed lymphedema in my right arm. Lymphedema is an accumulation of lymphatic fluid that causes tissue swelling, most often in an arm or leg, and occasionally in other parts of the body. Although lymphedema can strike anyone at any age, most cases are the result of cancer or cancer treatment. Over time untreated lymphedema can lead to disfigurement, disability, and even death.

Treatment for lymphedema includes all of the following: a light massage called manual lymph drainage (MLD), which redirects the fluid from the affected side to another healthy cluster of lymph nodes; light stretches and exercises; and the use of compression bandages and garments. These garments need to be worn 24 hours a day, are expensive, and must be replaced every four to six months. The first intensive round of treatment is usually administered by a certified lymphedema physical or occupational therapist and is followed up with self-care at home.

The diagnosis of lymphedema was much harder for me to accept than my cancer diagnosis. To me breast cancer seemed to have a starting point and an end point. Lymphedema, however, serves as an everyday reminder of what I have been through. I need to do self-MLD every day and wear compression garments by day and bandages at night. There is never a moment when I can just take my dog for a walk without wearing a sleeve and glove or sleep out somewhere without bringing bandages. Infection is another big concern, as the smallest cut or even a mosquito bite can cause a potentially fatal infection called cellulitis in my arm.

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and has given meaning to my life. I am now officially a five-year survivor, and I find that helping others navigate their cancer and lymphedema treatment enables me to deal with my own reality.

I am currently working for the National Lymphedema Network (NLN), a nonprofit organization dedicated to creating awareness of lymphedema, where I am very involved

in patient advocacy and in communication and education efforts for both patients and medical professionals. I also manage the Marilyn Westbrook Garment Fund, which provides lymphedema garments to patients who cannot afford them.

I am also working with the NLN on getting a new bill passed through Congress that will mandate that Medicare pay for lymphedema garments. An estimated 1.5 to 3 million Medicare beneficiaries are currently not receiving the treatment that they need because lymphedema garments are not covered. Medicare spends billions of dollars every year, however, treating largely preventable lymphedema-related cellulitis.

Through the tireless efforts of a small group of lymphedema advocates, patients, and medical professionals, we have gotten a House bill—H.R. 4662, the Lymphedema Diagnosis and Treatment Cost Saving Act of 2010—introduced by Congressman Larry Kissell from North Carolina. Since its introduction support for H.R. 4662 has been steadily building momentum. As of August 15, 2010, the bill had 50 co-sponsors distributed between both parties and genders. The bill has also been endorsed by more than 40 organizations, including LiveSTRONG® (the Lance Armstrong Foundation), the Colon Cancer Alliance, Living Beyond Breast Cancer, the Breast Cancer Network of Strength, and the Susan G. Komen for the Cure® Advocacy Alliance.

Despite the broad support we have enjoyed, we still need help. We need people to write to their representatives and ask them to co-sponsor this bill and to write to their senators to ask them to sponsor a companion bill in the Senate. For more information about how you can help H.R. 4662, please visit www.lymphedematreatmentact.org.

For more information about lymphedema and the Marilyn Westbrook Garment Fund, visit the National Lymphedema Network's website at www.lymphnet.org.

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