

# Guest columnist: Health insurance shirks its duty to women with breast cancer complications

Karen Chavez GUEST COLUMNIST 11:46 a.m. EDT October 21, 2016



(Photo: Angeli Wright/awright@citizen-times.com)

When I wear sleeveless tops, there isn't a day when I'm not asked about my lymphedema garments.

These are a full-length sleeve and a fingerless glove on my left arm.

"Do you golf?" "Are you a bowler?" "What's wrong with your arm?" and even, "Cool sleeve, where did you get it?"

Um, the Asheville Orthopedic Appliance Co.

I wear the garments, not as a fashion statement, not to bowl, but to control the non-stop pain and swelling in my left arm and hand, known as lymphedema.

Over the past three years of wearing the garments, I now use the questions as a teaching moment.

Lymphedema is a chronic disease that results in a backup of lymph fluid (which carries away the waste from the blood stream). It occurs when the lymphatic system is damaged, said Emily Jones, an occupational therapist at CarePartners.

In my case, the damage was caused by breast cancer surgery and the removal of lymph nodes from under my arm.

There is no cure for lymphedema. Once you have it, you have it forever.

An estimated 3 million-5 million people Americans suffer from lymphedema. Two out of five breast cancer patients will develop lymphedema within five years of surgery.

With lymphedema, I cannot type. I wouldn't be able to write this story, which is my livelihood.

But there is treatment. The two most effective are manual lymphatic drainage, performed by a physical therapist specializing in lymphedema, and compression garments.

The garments require a doctor's prescription and are custom made. They are about \$328 for one sleeve and one glove. I need two at a time, \$656 – one to wear while the other is being washed. (They are tight to the skin, get sweaty and dirty and need to be changed daily, kind of like underwear).

I need new pairs twice a year because they stretch out, get damaged and then are no longer effective. That's about \$1,312 a year. It is cost prohibitive.

My former health insurance paid for them. My new insurance company – Blue Cross Blue Shield of Texas – does not cover compression garments.

When I told the BCBS customer service person that I have breast cancer and cannot function without them and can't afford them, on top of my ever-growing mountain of breast cancer-related debt, she said "those are the rules."

Well, North Carolina has its own rules. Actually, it has a law. Passed by the General Assembly in 2009, HB 535 states that every health benefit plan in the state must provide coverage for the diagnosis, evaluation, and treatment of lymphedema, including benefits for equipment, supplies, complex decongestive therapy, and *gradient compression garments*.

North Carolina and Virginia and the *only* two states in the country with such laws. Bravo.

I told the BCBS rep about that and that the N.C. law should cover me. She said it did not, since the company is based in Texas.

Sound barbaric?

Heather Ferguson thought so. A mom of two from Charlotte, one of her sons was born with primary lymphedema in both legs. He was prescribed his first compression garment at age 7 months. Ferguson's insurance denied it.

Not a woman to be messed with, Ferguson reached out to her state representative, Tricia Cotham, D-Mecklenburg. Cotham helped Ferguson with the appeal, which only gave her one year of payment. Now 10, he needs to wear the knee-high socks every day. He will need them for life.

Ferguson continued to work with state representatives until the lymphedema law passed. She formed the Lymphedema Advocacy Group.

Now she has taken her cause to Congress.

Introduced in 2010, the Lymphedema Treatment Act would amend a section of the Social Security act to provide for Medicare coverage for lymphedema compression items. That would extend to all states, even Texas.

The bill has 249 House co-sponsors, including Rep. Mark Meadows, R-Jackson, and 28 senators, including Thom Tillis. Sen. Richard Burr has not signed on.

“It already has a large amount of bipartisan support,” Ferguson told me. “It’s a win-win for everyone. It improves patient care and quality of life, and provides a net saving to Medicare. We’re paying for so many things that can be prevented if we manage the disease from the start.”

Even with my sleeve and glove, I often have to raise my arm to further control the swelling. Then people ask, “Do you have a question?”

Yes. Why won’t my health insurance pay for my lymphedema sleeves?

*This is the opinion of Karen Chávez, reporter for the Asheville Citizen-Times. Email her at [KChavez@Citizen-Times.com](mailto:KChavez@Citizen-Times.com) and follow @KarenChavezACT.*