The battle after breast cancer

Lymphedema garments can cost patients battling the condition thousands of dollars a year -- out of pocket. Jeannie Blaylock reports on the push to get the garments covered by Medicare. Jeannie Blaylock

Click on picture at left to view video

JACKSONVILLE, Fla. -- It's embarrassing. It hurts. It's expensive.

Lymphedema throws some people into a bad battle after breast cancer. But now you can help with just a click online. It won't cost you a penny to support the Lymphedema Treatment Act.

Basically, there's a push in Jacksonville and nationwide to rally lawmakers in Washington to pass a bill to change Medicare so it will pay for compression garments for lymphedema patients.

The garments are necessary to manage lymphedema. Without them, a patient's hand or arm or leg can swell to enormous sizes. The garments can cost up to $2,000 a year out of pocket.

Supporters are asking you to send the link out on your Facebook and Twitter pages. SHOW YOUR SUPPORT

Downloaded August 27, 2014 from First Coast News.com web site:
On the page, you'll find a place to click to tell your representative that he or she should co-sponsor the bill so it comes up for a vote in Congress.

You can help by just going to lymphedematreatmentact.org and sending a message to Congress. (Photo: FCN)

Joann Simon of Jacksonville is in tears talking about trying to pay for her compression garments. She even took a janitorial job to earn extra funds because "I hate to ask people to give me money." Her garments cost about $900 per year.

Jacksonville advocate Candace Bridgewater says she's been dealing with lymphedema for 16 years. As she explains, "It's a swelling."

The lymphatic system becomes blocked after surgeons perform an axillary node dissection to see if the cancer has spread into the lymph nodes. How exactly lymphedema happens is not clear. But the more lymph nodes tested for cancer, the higher the risk. That explains why the commonly-used Sentinel node biopsies have a lower risk for lymphedema. Doctors take out fewer lymph nodes to test in that procedure.

Here's an important point, however. Most breast cancer patients do not get lymphedema. So worrying that you might get a swollen limb should never prevent you from getting a mammogram or doing a self-breast exam. The threat of breast cancer undiagnosed is much more dangerous to you.

That being said, lymphedema is a nasty challenge for patients who get it.

It can pop up a few months after breast cancer treatment or even a few decades.

It can never be totally cured.

However, Deborah Headley, a physical therapist who works with lymphedema patients at Baptist Health, says people need to feel optimistic that lymphedema can be "managed." She adds that "obesity" is -- for some unexplained reason -- an added risk factor for getting lymphedema.

According to the National Cancer Institute, the numbers of people who get lymphedema range from 8% to 56% among women two years out from breast cancer surgery. The NCI calls it "one of the most poorly understood, relatively underestimated, and least researched complications of cancer..."
Bridgewater says it can happen with other types of cancer -- from female cancers to prostate cancer. Children can be born with primary lymphedema, with their toes and hands swollen to huge sizes.

It can also happen after an injury or infection when there’s no cancer present.

So the Lymphedema Treatment Act in Congress wouldn't just help adults, but children too.

Bridgewater says she and other supporters from around the country will travel to Washington next month to lobby congressional members.

Meanwhile, she says, please add your support to the cause.

If you need help with lymphedema, contact the Jacksonville Lymphedema Clinic behind Memorial Hospital or its web site: http://www.jaxlymph.com/