

Pain of swollen arms hits breast cancer patients in the pocket

Few insurers cover compression garments needed to treat lymphedema

October 13, 2011|Susan Reimer

It can be one of the nasty surprises for breast cancer patients.

After the lump, the biopsy, the surgery, the radiation and the chemo, the wig and the mastectomy bathing suit — as if these things were not enough — suddenly one arm, or both, swells monstrously, painfully.

It is lymphedema. And nobody warned you about it.

"I never expected it. I never even heard of it," said Tia Neale, a breast cancer patient who lives in Owings Mills.

She is resting on an examining table at Mercy Medical Center's Weinberg Center while therapist Maureen McBeth gently massages her chest, stomach, arm and hand, doing manually what Neale's lymphatic system isn't doing on its own anymore — urging the fluid the body makes ceaselessly into the circulatory system and out of the body.

The massage treatment takes about an hour and Neale travels to Mercy two to three times a week — she used to come daily — to control the swelling.

As soon as McBeth finishes, she helps Neale wrestle her arm and hand into a tight-fitting sleeve and glove. Called compression garments, they will continue to do what McBeth's gentle fingertips have been doing.

Neale must wear the sleeves 24 hours a day, probably for the rest of her life. Lymphedema — the result of damage or removal of lymph glands during breast cancer treatment — can be controlled, but it can't be cured.

"It's not like you can put lymph nodes back," said McBeth, who manages cancer rehab for Mercy. "For more people, this is lifelong."

The compression garments cost anywhere from \$50 to \$2,000 each. The average might be about \$400 a set. Most must be custom-made to fit the patient's measurements. You need two so one can be washed, and a different, specialized garment to wear at night. You might need to replace them every six months.

And here is the other nasty surprise: Medicare doesn't pay for these compression garments and, because Medicare sets the coverage standard, almost no private insurers pay for them either. Or they pay very little.

"It is adding insult to injury," said McBeth, who massages more than her patients' hands and arms. She works whatever angles she can to find private money to help her patients pay for these garments. Mercy has its own fund for patients, as some hospitals do, but it is inadequate.

"Every soccer-playing kid in America has a pair of spandex shorts, and my patients can't get the garments they need," she said.

There is a bill in Congress, HR 2499, called the Lymphedema Diagnosis and Treatment Cost Saving Act, that would require Medicare to cover the diagnosis and treatment of lymphedema, including the manual lymph draining that McBeth does and the compression garments that can be so expensive. Such a change in Medicare coverage would likely trigger a similar change among private insurers.

None of Maryland's representatives in the House is listed as a co-sponsor of the bill and there is no companion bill in the U.S. Senate. McBeth said she can't get any of the state's politicians to visit her clinic, meet her patients or see what is needed. The talk of spending any more money on health care must just spook politicians these days.

"It is insulting that Medicare would cover erectile dysfunction and not this," said McBeth. "Compression is the only thing that works. There is no medicine and there is no substitute. It is medically necessary, and it isn't covered."

Lymphedema is not just another embarrassing disfigurement caused by [breast cancer](#). And discomfort and limited range of motion are not the only side effects.

The protein-rich fluid that collects under the skin is the perfect breeding ground for cellulitis, an aggressive infection that can be provoked by something as simple as a paper cut and can require weeks of hospitalization and heavy-duty antibiotics.

Its early and energetic treatment is just the kind of preventive care that can keep any number of the estimated 1.5 million to 3 million sufferers covered by Medicare out of the hospital, a potential savings of millions of dollars.

A change in the law would do something more. It would produce a change in awareness. Most breast cancer patients, like Neale, never heard of lymphedema because their doctors never brought it up.

To be fair, a diagnosis of breast cancer produces a laundry list of important matters to be discussed. But McBeth is convinced that pre-treatment measurements and careful monitoring after treatment can manage the swelling and the pain and reduced mobility that so often result.

Neale, who could not lift her arm above her head, now has full range of motion.

"I know I can help every patient I see," said McBeth, who lectures nationally on treating lymphedema. "But I don't have the resources and my patients don't have the money. I shouldn't have to say that I wish I'd win the lottery to take care of them."

For more information on lymphedema and HR 2499, visit lymphnet.org

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