

Bringing attention to the suffering of swelling

Kimberly Rubenstein

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MEEGAN M. REID

Susan Wright's fight with endometrial cancer ended nine years ago, but she faces a lifelong battle that's a result of doctors removing 27 pelvic lymph nodes to ensure she was cured of the disease.

The battle isn't against a tumor, but against disfiguring swelling she's prone to as a result of her lymph nodes being removed. A cut or scrape could lead to infection that causes her legs to balloon to multiple times their normal size. Overexertion or staying too sedentary could upset the flow of lymph fluid, which no longer moves normally in her body on the side where the nodes were removed, causing the swelling.

The condition is called lymphedema, and it's one that Wright, 60, of Gig Harbor, has had to learn to live with. It involves regular trips to therapists who manually move the lymph fluid; vigilance in avoiding cuts on her legs or feet (she doesn't go barefoot); and wearing thigh-high compression hose most hours of the day — the worst part for Wright.

"In my early 50s, I didn't see myself wearing something like that," she said. "In the summer, it's like wearing long underwear."

Cancer survivors and others who suffer from the condition — including some who are born with it — say little attention is given to the disease, despite its prevalence. Advocates fighting on behalf of lymphedema sufferers say that of the nearly 240,000 men and women who get breast cancer this year, 40 percent will end up with lymphedema at some point after treatment.

HOW IT OCCURS

Removal of lymph nodes during surgery for cancer allows doctors to see if a cancer has spread. But the lymph nodes don't grow back, depriving the overall lymph system of points and routes to filter harmful substances that eventually need to be returned to the bloodstream.

The result is fluid buildup in the tissues, which causes the pain and swelling of the limbs. Without proper treatment, the limbs will not go back to their normal size — and sometimes the damage is irreversible.

For years, lymphedema seemed to fly low on the radar of medical practitioners, said Bonnie Pike, a Tempe, Arizona, breast cancer survivor who now advocates on behalf of lymphedema sufferers. She ended up diagnosing herself after she could not find a doctor or surgeon who could identify the disease.

"Doctors don't have a lot of experience with it, and nobody 'owns' it," Pike said. "Oncologists don't own it, surgeons don't own it."

She points to surveys of medical schools that show relatively little time is spent educating future doctors on the lymphatic system.

Melissa Mercogliano, doctor of physical therapy and owner of the Center for Orthopedic and Lymphatic Physical Therapy in Port Orchard, discovered the reality when she started her career. She was treating many women who were cancer survivors and had the condition. She began specializing in the treatment of lymphedema in the late 1990s. Part of the treatment involves a special massage that moves lymph fluid to nodes that are still functional, called Manual Lymphatic Drainage.

The onset of lymphedema means several visits each week to a physical therapist, occupational therapist or massage therapist trained in the drainage technique. Following that, the affected limb is wrapped in compression bandages to reduce swelling — and must be wrapped and re-wrapped for several days or weeks. Once the swelling has reduced and the size of the limb has stabilized, the patient is fitted for skintight compression garments that they will wear every day for the rest of their life.

“It requires lifelong management,” said Mercogliano, who treats a wide array of patients affected by lymphedema, including those who have experienced orthopedic trauma or surgery or repeated infections. “It’s kind of like being diabetic,” she said, adding that self-massage and using the compression garments are a daily ritual for sufferers.

FOUND RELIEF

The condition still eludes many physicians today. Ron U’ren, 69 of Port Ludlow, is a patient at Mercogliano’s clinic. For years he suffered from the swelling with no relief, getting frequent infections and having to medically retire from his job at Boeing. He wore compression stockings, but physicians never referred him to a therapist for treatment.

He was recently referred to the practice after switching to a new podiatrist. He has seen his legs reduce in girth by almost roughly a third. He can now touch his toes and walk to get exercise during the day.

“I have started to lose weight ... to get more physical,” he said.

The awareness seems to be spreading among surgeons and oncologists working with breast cancer patients. That’s been the experience for Kathryn Simpson, a South Kitsap resident who was diagnosed with breast cancer in August 2013. After she went through chemotherapy and was preparing for surgery, her surgeon brought it up and recommended the preventive steps of physical therapy. She was treated by Mercogliano and wears a compression sleeve to ward off lymphedema when she is active. She is on guard against any sign of swelling; she’s acutely aware that a cut or bee sting could throw her system off balance and cause lymphedema.

“It’s definitely a different paradigm than the carefree self I used to be,” she said.

Even for those aware of the condition, there are barriers for treatment. Pike said that finding a practitioner to treat it can be difficult, and that it’s important to look for a therapist that has specialized training in Manual Lymphatic Drainage.

“Anyone with a PT (physical therapy) or OT (occupational therapy) license is allowed to treat it, but they don’t have to know anything about it,” she said.

Massage therapists can also be trained in the technique. Mary Briner, who practices at Well Being Health Center in Poulsbo, has been certified in a specific type of Manual Lymphatic Training. She said it’s a rare certification for massage therapists because of the time and expense of the training.

The lack of insurance coverage can also be a barrier. While companies might cover treatment by an occupational or physical therapist, compression bandages and garments (which can cost thousands of dollars) are often not. Sufferers have formed the Lymphedema Advocacy Group to lobby lawmakers in Washington, D.C., to pass a bill that requires Medicare coverage of all aspects of lymphedema treatment — therefore setting a precedent for Medicaid and private providers.

HOPE FOR SUFFERERS

Pike feels there is hope for lymphedema sufferers. She points to a \$2 million grant the National Institutes of Health awarded last year to Georgia Tech to better understand the underlying causes of lymphedema. She’s hopeful that more research into how the lymphatic system works will help improve treatments, even if a cure is not in sight.

Mercogliano said there are local doctors who are educated on the condition and refer patients to her before the onset of lymphedema. “We catch them and teach them to watch for it before it gets too significant,” she said. Her hope is that awareness on the part of doctors and patients would continue to increase so that fewer would suffer before getting treatment.

For those who she does care for who have long had the condition, hope comes in progress against the swelling. During a recent appointment, Mercogliano remarked at how much smaller U’ren’s legs were, decreasing in circumference from 62 centimeters to 40 centimeters.

“Your lymph system is going to work so much better,” she said.

“Now my legs aren’t slowing me down,” U’ren replied.

RESOURCES

- National Lymphedema Network: <http://www.lymphnet.org/>
- Lymphedema resources for breast cancer survivors: www.stepup-speakout.org
- Resources on the disease and fight for insurance coverage: <http://lymphedematreatmentact.org>
- Society for Oncology Massage: <http://www.s4om.org/>

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