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Downsizing Swollen Limbs

BY KATHERINE HOBSON

Lymphedema treatment works—even years after onset.

Nancy Abramson had already been through a lot: breast cancer in 2000 that required a mastectomy, chemotherapy, and radiation; and then reconstruction in 2001.

She was just getting back to her routine when she noticed that a bracelet and ring she used to wear no longer fit. The swelling, which also involved her arm, was accompanied by a feeling of heaviness. The diagnosis: lymphedema, a backup of lymphatic fluid resulting from damage to lymph nodes.

While “primary” lymphedema can occur spontaneously anywhere in the body at any time, “secondary” lymphedema is sparked by trauma, including radiation or surgical removal of lymph nodes—both common treatments for a number of cancers, including head and neck, prostate, testicular, cervical, breast, and melanoma.

Breast cancer patients such as Abramson, 59, are particularly vulnerable to lymphedema in the arm because they had axillary node dissection, the removal of some or all of the lymph nodes in the underarm area to determine the extent to which the cancer has moved outside the breast. This information helps determine staging of the cancer and could impact treatment choices. Performing axillary dissection on all women meant that those whose nodes were clear of cancer were unnecessarily put at risk for lymphedema.

Now the standard of care for breast cancer, sentinel node biopsy removes only the node or nodes closest to the breast. Only if the sentinel node contains cancer cells does the surgeon remove remaining nodes in the underarm, and if the sentinel node is negative, studies have shown better than a 90 percent chance of no further nodes being involved.



A ring and bracelet, too tight to wear, were Nancy Abramson's first indicators of lymphedema. Photo by Jennifer O'Donnell

According to a 2007 study that enrolled close to 1,000 women, between 3 and 5 percent of patients who have a sentinel node biopsy will get lymphedema compared with 16 to 27 percent of those who have full axillary dissection. The wide variation in incidence is due to multiple factors, including the number of nodes removed, how researchers define lymphedema, and measurement difficulties. Radiation to the breast can, in some cases, increase the possibility of lymphedema because of injury to the nodes and lymphatic channels.

But whether lymphedema arises quickly or years after treatment, it can be managed with conventional techniques, plus some new ones.

Flushing Out the System

The lymph system absorbs fluid from tissues throughout the body and shunts it into increasingly larger vessels, explains Nicole Stout Gergich, PT, a physical therapist and certified lymphedema therapist at the Breast Care Center at the National Naval Medical Center in Bethesda, Maryland.

This protein-rich fluid passes through lymph nodes, which remove impurities, and is eventually flushed from the body. If the lymph nodes are removed or damaged, the fluid backs up.

Stout Gergich explains that because the lymph fluid isn't taking away bacteria and other infection-causing elements from the tissue, those areas where the fluid gets congested are prone to infection called cellulitis that, if not controlled, can require hospitalization for intravenous antibiotics.

The onset of lymphedema is unpredictable, Stout Gergich says. In some cancer patients it appears shortly after surgery; in others undergoing the same surgery, not at all.

Stout Gergich says that historical research has shown that with breast cancer, the majority of people who are going to get lymphedema will get it in the first three years. "But in some people 20 years out, suddenly they get an infection and

develop lymphedema for the first time.”

Growing Awareness

Though awareness among physicians has grown to the extent that some cancer centers have lymphedema specialists, patients in the past were often met with clueless stares from their physicians when they complained of swelling.

Glenn Lang underwent surgery and radiation for testicular cancer in 1963 and developed lymphedema so severe that he had to have special trousers made to accommodate his swollen leg. His physician suggested a stocking, which didn't help. Lang, a construction worker, ultimately had to go on disability.

More than 30 years later, a colleague referred Lang to a therapist near his Michigan home who specialized in working with breast cancer survivors. She was able to reduce the swelling significantly, allowing Lang to resume many normal activities.

This doesn't mean Lang or anyone with lymphedema can be cured—but lymphedema can be treated and managed even years after onset by using complete decongestive therapy (CDT), a labor-intensive, time-consuming, multi-faceted process, explains Saskia Thiadens, RN, executive director of the National Lymphedema Network, a nonprofit advocacy group.

The process includes a number of steps, beginning with manual lymphatic drainage, a form of massage performed by a certified therapist that stimulates the lymphatic system to move lymph fluid and bring down swelling. The second step is precise bandaging designed to encourage the continued flow of lymph. While effective, the bandaging during initial treatment is difficult both physically and emotionally. Abramson recalls spending a Thanksgiving holiday watching other people prepare the meal she was used to making while her arm and hand were swaddled in bandages. “It was very frustrating,” she says.

““ People with lymphedema have an increased risk of infection ... I don't want my patients to be paranoid, but I want them to be prudent.””

—Leslie J. Waltke, PT

Once the swelling is under control, patients keep it from returning by wearing a custom-made compression garment during the majority of the day while bandaging at night.

Sequential pumps, which use a sleeve that has chambers that fill sequentially up the limb to move lymph fluid, have, for the most part, been replaced by CDT as the primary treatment to reduce swelling, says Thiadens, who adds that the pumps can still be helpful when used in conjunction with other modalities and if used under close supervision of a therapist.

New York City resident Linda David, who developed lymphedema in her left leg a few years after treatment for cervical cancer in 1984, uses compression stockings and nightly wrapping to control her condition between two-week intensive physical therapy sessions a few times a year.

Because any skin problem can result in infection, therapists recommend gloves for gardening, care when using any sharp object, immediate application of antibiotic for any skin break, and insect spray when outdoors.

“People with lymphedema have an increased risk of infection,” explains Leslie J. Waltke, PT, regional cancer rehabilitation coordinator for Aurora Health Care at Aurora Sinai Medical Center in Milwaukee. “If a normal human armpit has 35 or 40 nodes and you’ve lost half, a little teeny bug or bacterium that would have been destroyed by an intact lymphatic system can every once in a while cause a problem. I don’t want my patients to be paranoid, but I want them to be prudent.”

New Approaches for Control

Cancer patients who developed lymphedema decades ago were warned to avoid using the extremity, while today they are encouraged to exercise. Indeed, today numerous clinical trials are exploring effectiveness of exercises such as swimming.

“Exercise can create a pumping effect on the lymph system, which stimulates the lymphatic flow,” says Waltke, pointing to studies presented at the National Lymphedema Network’s recent international conference, where researchers reported that exercise, even high-intensity weight training, doesn’t exacerbate the condition, but may contribute to weight loss—important because weight gain is emerging as a surprisingly significant factor in developing lymphedema, says Waltke.

As for intensity, Stout Gergich says that just as those who have had a coronary bypass are told to exercise appropriately, it’s no different with lymphedema. “You can weight lift, rock climb, kayak—you can do whatever as long as you have consideration for your limbs.” That means self-monitoring for signs that lymphedema might be looming, such as swelling, a feeling of fullness, tingling, or pain in the affected area.

Abramson takes part in twice-weekly classes of the Lebed Method, a therapeutic exercise program incorporating movement and dance, developed by breast cancer survivor Sherry Lebed Davis, who also has lymphedema.

The movement in the Lebed Method program is structured to stimulate lymphatic flow. Developed with her two brothers, who are physicians, the program is now affiliated with numerous cancer centers across the country.

Lebed Davis encourages people not to be afraid of lymphedema; there may not be a cure, but that isn’t reason for despair, she says. “I had it in my arm, my chest, my back—but if you saw me now, you wouldn’t know it.”

She participates in many of the activities she did before lymphedema, including golf, but wears a compression sleeve on her arm and hand. She is constantly

watching for signs that she needs to stop an activity. “So sometimes I can do all 18 holes, and sometimes it’s just nine. I always say: You don’t have to give up your life, you just need to know how to manage it.”

To locate a therapist trained in complete decongestive therapy, go to the National Lymphedema Network at www.lymphnet.org