

# Managing lymphedema, a lingering problem for breast cancer patients

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The prospect of lymphedema provokes substantial anxiety for many patients with breast cancer. For them, developing lymphedema can be worse than the cancer itself; it is a chronic problem that is time-consuming to manage and a constant reminder of their disease. The condition can limit patients' activities and choice of clothes, often resulting in dramatic life changes. When healthcare professionals listen to patients' concerns and provide information and referrals for appropriate treatment, it can lower these women's level of distress and improve their quality of life.

**For a patient's point of view, see page 307.**

**L**ymphedema is a chronic condition in which there is an abnormal accumulation of protein-rich fluid in the subcutaneous tissue of the arm, hand, breast, or chest wall after lymph node removal and radiation treatment for breast cancer. The condition can develop months or even years after treatment. The incidence of lymphedema among breast cancer patients varies from 6%–30%.<sup>1</sup> The longer patients are followed and the more strict a definition of lymphedema is applied, the higher the incidence rate. Patients undergoing sentinel node biopsy have a lower risk of developing lymphedema than those who undergo a full axillary lymph node dissection.<sup>2</sup> But all women with

breast cancer need to be educated about the lymphatic system, the possibility of lymphedema, and the problematic symptoms that can occur.

## Lymphatic breakdown

When there is a buildup of tissue fluid that overtaxes an individual's lymphatic system, the valves in those vessels become stretched. The vessels no longer effectively carry tissue fluid from the limbs, and part of the limb or even the entire limb, can become swollen. An increase in tissue fluid that leads to a breakdown in the lymphatic system can result from:

- A constriction (eg, a blood pressure cuff or tight jewelry) that might damage tiny lymphatic vessels and trigger a buildup of tissue fluid;
- An infection that causes increased fluid in the area;
- Strenuous exercise that results in additional fluid and nutrients directed toward the working muscles; and
- Vigorous massage and heat that result in a dilation of blood vessels and thereby encourage increased fluid to flow from the blood vessels to the tissue.

## Treatment options

Treatment options for lymphedema vary based on the patient's medical history, the severity of swelling, and the patient's determination to take part in a treatment program (Table 1). Manual lymphat-

### KEY POINTS

Postmastectomy lymphedema is a chronic condition that can develop months or even years after treatment.

To limit the risk of developing lymphedema, all patients who have been treated with axillary node dissection, sentinel node biopsy, or radiation therapy should be educated about the lymphatic system and basic precautions.

Trained occupational, physical, and massage therapists can help manage lymphedema, but currently only occupational and physical therapies are reimbursed by most insurance plans.

The benefits and risks of using compression garments prophylactically for air travel in breast cancer patients should be discussed with each patient.

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ic drainage (MLD), a mainstay of lymphedema therapy, is the most intensive form of therapy and consists of daily treatments for 2 or more weeks. It is a gentle technique to stimulate the lymphatic system and redirect stagnant fluid from the congested area toward a functioning part of the system. At the conclusion of this intensive phase, patients are taught a home management program to help maintain the reduction in edema.

An alternate strategy is to employ a home management program at the outset of treatment. Depending on the case, the home program can be simple or more complex. On average, one to three 1-hour sessions are necessary to establish an independent home program. Since lymphedema is a chronic condition, patients will require ongoing follow-up to review the program and make necessary modifications as well as to check and replace garments approximately every 6 months.

**For every scenario, a type of therapist**

Referral to an occupational, physical, or massage therapist is appropriate if a patient is complaining of any discomfort or swelling after breast cancer treatment. But first, a physician should rule out infection, a blood clot, or other cause of the swelling before involving one of these professionals. Because lymphedema management is not commonly part of the coursework in programs of these types of therapists, additional postgraduate training is needed to effectively treat this condition.

Each of these professionals might measure patients for compression garments, teach bandaging, and provide lymphatic massage and exercise as part of the treatment plans. Currently, physical and occupational therapies are generally covered by health insurance, whereas massage therapy may not be.

Although occupational, physical, and massage therapists utilize similar

treatment techniques to help patients control the swelling and discomfort of lymphedema, each type of professional has a slightly different treatment focus. **What follows are descriptions of each professional’s different types of focus, sample types of cases seen by each therapist, and the treatment approach each typically would take.**

*Occupational therapy*

Occupational therapists concentrate on the physical, cognitive, and emotional effects of breast cancer treatment that prevent patients from taking part in daily activities.

**A patient reports that her arm swells during the day and feels tired, so she has trouble completing tasks assigned to her at work and her household chores. She adds that she does not want to wear her sleeve at work because it is uncomfortable and embarrassing.**

The occupational therapist talks with the patient about her daily routine. Together they establish an alternative plan for using her sleeve and find ways to modify her activities so she can continue to function both at work and at home. The therapist also helps the patient find a different, more comfortable sleeve and role-plays with the patient to give her ideas for responding to intrusive questions from coworkers or strangers. During the treatment, the occupational therapist reviews the patient’s home management program, which includes nighttime bandaging and exercise.

*Physical therapy*

Physical therapists focus on limitations in range of motion, muscle strength, flexibility, and movement caused by the swelling.

**A patient has significant swelling that is not responding to daily use of a compression sleeve.**

This type of patient might benefit from a course of MLD. After the physical therapist performs lymphatic massage, the patient is wrapped in

**TABLE 1**

**Treatment options for patients with post-mastectomy lymphedema**

- Moisturize and protect the skin daily to help avoid infection.
- Wear a compression garment (sleeve, glove, or compression bra) every day.
- Wrap the arm (and hand, if needed) with specialized lymphedema bandages.
- Undergo manual lymphatic drainage (MLD) therapy to redirect fluid to a functioning part of the lymphatic system.
- Perform daily self-massage or have a friend or family member perform a gentle massage to the affected and adjacent areas.
- Perform prescribed daily exercises.

bandages and encouraged to perform exercises to reduce edema as much as possible. Once the swelling has stabilized, the therapist teaches the patient self-massage to incorporate into her home management program and refers her to a surgical supply store for a new, smaller compression garment.

*Massage therapy*

Massage therapists focus on using lymphatic massage to decrease the pain and discomfort of lymphedema.

**One patient reports feeling heaviness, aching, and fatigue in her affected arm and hand. Although she uses a compression garment every day and**

**Early, subclinical lymphedema symptoms**

Patients may report some of these symptoms even before any clinically evident swelling is present. Addressing these symptoms early on can help patients protect themselves from the more serious and debilitating consequences of chronic lymphedema.

- Heaviness, aching, tightness, and fatigue in the affected arm.
- Swelling or fullness in the arm, hand, breast, or chest wall on the side of the surgery.

## Position statement of the National Lymphedema Network: lymphedema risk reduction practices

### Skin care—Avoid trauma/injury and reduce infection risk

- Keep extremity clean and dry.
- Apply moisturizer daily to prevent chapping/chafing of skin.
- Attend to nail care; do not cut cuticles.
- Protect exposed skin with sunscreen and insect repellent.
- Use care with razors to avoid nicks and skin irritation.
- If possible, avoid punctures such as injections and blood draws.
- Wear gloves while doing activities that may cause skin injury (ie, gardening, working with tools, using chemicals such as detergent).
- If scratches/punctures to skin occur, wash with soap and water, ap-

ply antibiotics, and observe for signs of infection (ie, redness).

- If a rash, itching, redness, pain, increased skin temperature, fever, or flu-like symptoms occur, contact your physician immediately.

### Activity/lifestyle

- Gradually build up the duration and intensity of any activity or exercise.
- Take frequent rest periods during activity to allow for limb recovery.
- Monitor the extremity during and after activity for any change in size, shape, tissue, texture, soreness, heaviness, or firmness.
- Maintain optimal weight.

### Avoid limb constriction

- If possible, avoid having blood pressure taken on the at-risk arm.

- Wear loose-fitting jewelry and clothing.

### Compression garments

- Wear a well-fitting garment.
- Support the at-risk limb with a compression garment for strenuous activity (ie, weight lifting, prolonged standing, running).
- Wear a well-fitted compression garment for air travel.

### Extremes of temperature

- Avoid exposure to extreme cold, which can be associated with rebound swelling or chapping of skin.
- Avoid prolonged (> 15 minutes) exposure to heat, particularly hot tubs and saunas.
- Avoid immersing the limb in water temperatures above 102 °F.

Copyright © 2005 by the National Lymphedema Network, 1-800-541-3259, www.lymphnet.org. Reprinted by permission. For position papers on other topics (training lymphedema therapists, exercise for lymphedema patients, and air travel and lymphedema), see www.lymphnet.org/aboutNLN/positionPapers.htm.

The Network is a non-profit organization founded in 1988 by Saskia RJ Thiadens RN, to provide education and guidance to lymphedema patients, healthcare professionals, and the general public. In addition, the Network supports research on the causes and possible alternative treatments for lymphedema.

performs some exercises every night after wrapping her arm, she continues to experience discomfort regularly.

Another patient is at high risk for developing lymphedema due to the large number of lymph nodes that were removed and radiation therapy to the axilla. Although she currently has no swelling, she is concerned about the intermittent heaviness in her arm.

In each of these types of cases, the massage therapist provides intermittent lymphatic massage to help reduce the swelling, stimulate alternate lymphatic drainage pathways, and temporarily alleviate symptoms.

### Risk-reduction strategies

Currently, there is no consen-

sus about the best ways to prevent lymphedema. Some patients have been instructed not to lift or carry more than a certain amount of weight, whereas others have been told to resume all prior work, self-care, and leisure activities without restrictions. Since it is unclear whether any particular activity increases the risk for developing lymphedema, both approaches are reasonable.

One study that followed patients for 20 years after diagnosis of breast cancer did not link participation in any particular activity with the development of lymphedema. Weight gain and a history of infection after surgery were statistically significant variables in predicting lymphede-

ma.<sup>3</sup> However, patients often report the onset of lymphedema after repetitive or resistive exercise/activity or an injury to the arm. Other studies have shown that exercise does not provoke lymphedema and actually may be beneficial, helping to stimulate the lymphatic system.<sup>4,5</sup>

A general recommendation is for patients to continue to engage in their everyday activities but to make note of any heaviness, aching, fatigue, or swelling during those activities. If symptoms continue, patients should be evaluated by their physician and referred to a lymphedema therapist. If patients prefer a more cautious approach, they may choose to modify their activities with the help of an occupational

## Resources

Recently, the American Cancer Society published a comprehensive guide for patients entitled *Lymphedema: Understanding and Managing Lymphedema After Cancer Treatment*. The 180-page paperback costs \$16.95 and is available at: [www.cancer.org/bookstore](http://www.cancer.org/bookstore)

1-800-ACS-2345

[www.amazon.com](http://www.amazon.com)

By request at local bookstores

**National Lymphedema Network**

1-800-541-3259

[www.lymphnet.org](http://www.lymphnet.org)

**American Physical Therapy Association, Oncology Section**

1-800-999-2782 ext 8588

[www.oncologypt.org](http://www.oncologypt.org)

**The Lymphedema Awareness Foundation**

407-324-3255

[www.elymphnotes.org](http://www.elymphnotes.org)

**Northwest Lymphedema Center**

1-206-575-7775

[www.nwlymphedemacenter.org](http://www.nwlymphedemacenter.org)

therapist to limit the risk of developing lymphedema.

As a preventive strategy, a brief, daily exercise program is encour-

aged. Since there is a consensus in the lymphedema community that basic range-of-motion exercises are a helpful and vital component of treatment,<sup>6</sup> adding a 5-minute nonresistive stretching routine to the daily schedule is worthwhile.

### *Regarding air travel*

Because of the decrease in air pressure within an airplane cabin, and a resulting increase in tissue fluid, there is a theoretic link between the onset of lymphedema and air travel. But because most breast cancer patients do not develop lymphedema subsequent to air travel, it's not clear whether all patients who wish to fly should wear a compression garment prophylactically. Most lymphedema practitioners would recommend compression garments for women who have *already* developed lymphedema, but only some therapists encourage asymptomatic patients to purchase an inexpensive garment.<sup>7</sup>

The pros and cons of using a compression garment on an airplane flight to prevent lymphedema should be discussed with breast cancer patients. A patient's medical history and personal preference are key factors. It's important to note that an improperly fitting sleeve could actually provoke lymphedema, whereas a

well-fitting sleeve might help to support the lymph system.

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## *A patient's point of view*

# Lymphedema: 'It has changed everything I do'

Martha Domont, San Anselmo, California | As told to Randi Londer Gould

IN MARCH 2005, at age 52, I was diagnosed with infiltrating lobular carcinoma (ILC) in my right breast. Collectively, the masses were more than 9 cm in length and slow-growing.

From the beginning, I wanted a sentinel node biopsy because, through my own research, I knew

of the risk of lymphedema. I'm very athletic—I like to play tennis and golf, bike, hike, swim, etc, and I had seen women whose lymphedema left their arms and hands swollen. I did not want that to happen to me. Before operating, my surgeon checked with my oncologist to see whether he

could perform a sentinel node biopsy, but the oncologist insisted he remove multiple lymph nodes for diagnostic purposes. Feeling overwhelmed, I reluctantly acquiesced. In the end, 16 nodes were taken out—all of them cancer-free.

My treatment began with one

dose of doxorubicin and cyclophosphamide, which we changed to 5 rounds of cyclophosphamide, methotrexate, and fluorouracil, once every 3 weeks. I agreed with my doctors that I must have my affected breast removed. Because ILC has a tendency to file over to the opposite breast, I opted for a prophylactic double mastectomy. I then underwent 6 weeks of radiation therapy, 5 days a week. The radiation burned my skin and along with the surgeries scarred my tissues and tendons, making everything very tight. Consequently, I stretch several times each day now.

### Early warning

It wasn't until January 1, 2006, that I had my first full-blown bout of lymphedema. In retrospect, the warning signs appeared during the previous week. I noticed that from my wrist to my elbow, my tendon felt tight, but stretching didn't seem to help. It burned slightly, and I could not figure out what was going on. My wrist was a bit swollen, and my fingers were feeling tighter and tighter. I thought it was an infection.

On New Year's Day, I was at the athletic club my husband and I own. There had been some flooding (an ironic metaphor), so I was cleaning up when I suddenly looked down at my hand. It was so swollen it looked like a cartoon hand. It was huge, and the

swelling came on that quickly. I then put all the pieces together.

When one of my surgeons saw my swollen hand, he said, "Don't worry, that's not lymphedema. It will go away." But it didn't—at least, not right away and not completely.

It got to the point where I could not even hold a pencil. My arm and hand were swollen and throbbed constantly. On the inside of my index finger, there were bumps of protein-filled fluid that a physical therapist—who had only minimal training in lymphedema care showed me how to massage out. I have to do this religiously now, and it takes about 20 minutes each morning before I start my day. Massage to clear the lymph channels and swimming have definitely helped alleviate the swelling.

### Living cautiously

Now, everything I do has to be carefully considered: How could it affect my hand and arm? I can't wear jewelry due to the swelling. I have to wear an ugly and uncomfortable compression sleeve and glove daily while I work, exercise, garden, fly, hike—just about anything. If I pick up something that weighs more than a few pounds, it has to be with my left arm. If I go hiking, I need to walk with a tall stick to keep my hand held up high. If I play tennis, I limit the time I play and I have to hold my hand on top of my head for half an hour after-

ward. If I work out, I can only lift 3–5 pounds with my right arm; I used to lift much heavier weights—25 pounds or more. I can't sleep on my right side anymore. I have to be very careful about cuts, burns, scratches, bites, and manicures.

I'm definitely not as independent as I used to be. Lymphedema is constantly in my thoughts, and sometimes it depresses me beyond reason. After my treatments, I was anxious to leave cancer behind me. I got through everything that came my way, but now I have to carry lymphedema with me forever.

I feel that doctors have been insensitive about the effects of surgery and a little cavalier about removing so many lymph nodes unnecessarily. I implore the medical community to consider the quality-of-life issue and prevent more women from having to go through this depressing, lifelong struggle with lymphedema.

### Seventh National Lymphedema Network International Conference

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Nashville, Tennessee

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