



Lymphedema: What Every Woman With Breast Cancer Should Know

Hand and Arm Care After Surgery or Radiation Therapy for Breast Cancer

What is lymphedema?

During surgery for breast cancer, the doctor might remove one or more lymph (limf) nodes from the underarm area to see if the cancer has spread. When lymph nodes are removed, lymph vessels that carry fluid from the arm to the rest of the body are also removed because they route through and are wrapped around the nodes.

Removing lymph nodes and vessels changes the flow of lymph fluid in that side of the upper body. This makes it harder for fluid in the chest, breast, and arm to flow out of these areas. If the remaining lymph vessels cannot drain enough fluid from these areas, the excess fluid builds up and causes swelling, or lymphedema (limf-uh-**dee**-muh). Radiation treatment to the lymph nodes in the underarm can affect lymph fluid flow in the arm, chest, and breast area by causing scarring and damage, further increasing the risk of lymphedema.

Lymphedema is a build-up of lymph fluid in the fatty tissues just under your skin. It usually develops slowly over time. The swelling can range from mild to severe. It can start soon after surgery or radiation treatment. But it can also begin months or even many years later. Women who have many lymph nodes removed and women who have had radiation therapy for breast cancer have a higher risk of getting lymphedema.

Doctors still do not fully understand why some patients are more likely to have problems with fluid build-up than others. It's expected that in the future fewer women will develop lymphedema because:

- Breast surgery and treatment keep getting more conservative (that is, more women are treated with breast-conserving surgery, which removes the cancer and a small amount

of healthy tissue around it, rather than mastectomy, which removes the entire breast and more lymph nodes).

- Research advances have led to methods like the sentinel lymph node biopsy (a procedure that allows the surgeon to remove fewer lymph nodes).
- Newer studies are looking at finding which lymph nodes drain the arm before surgery so they can be saved when possible. This procedure is called axillary reverse mapping.

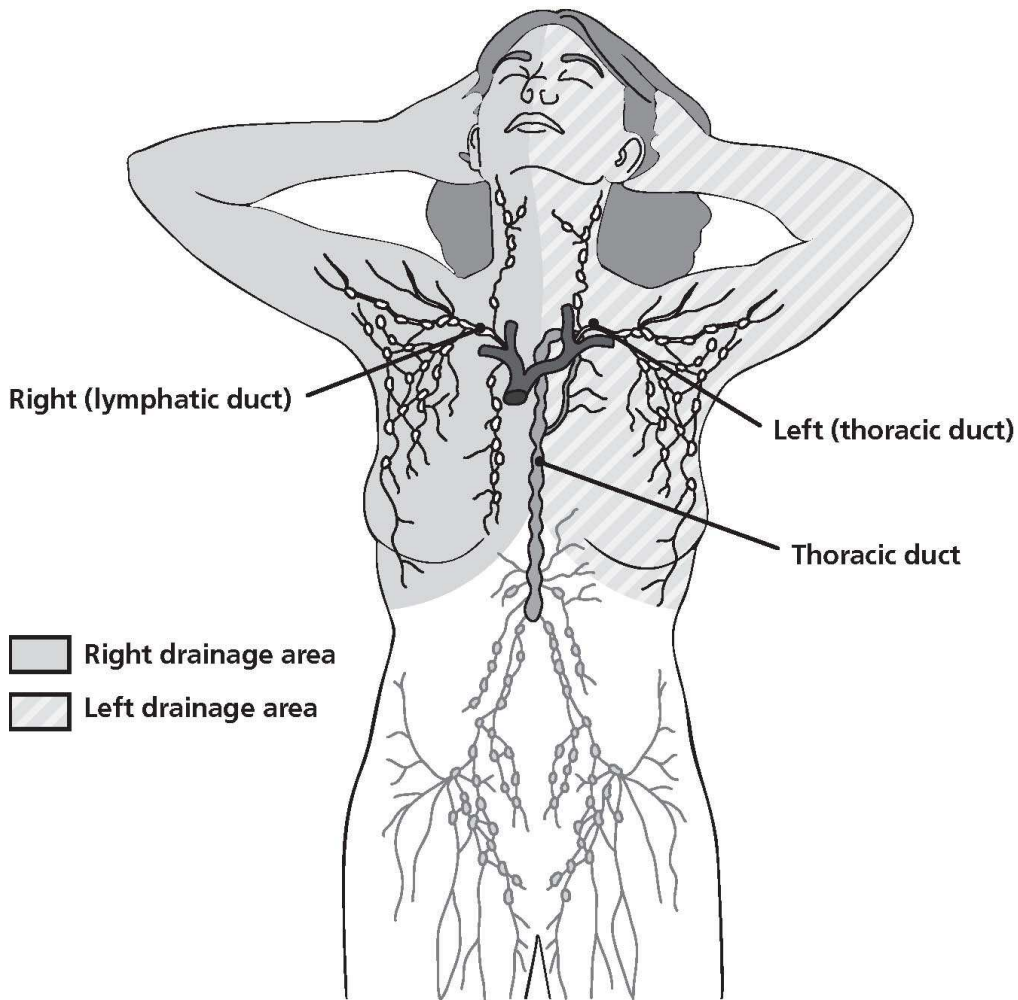
One type of lymphedema that does not seem to be decreasing, and may even be on the rise, is breast edema. It's possible that this is because more women are being treated with breast-conserving surgery and chest wall radiation than in the past.

There's still a lot to be learned about lymphedema, but there are ways that you can care for your arm and breast area to reduce your chances of having future problems. Once lymphedema has started, it cannot be cured. But early and careful management can reduce symptoms and help keep it from getting worse. In fact, some women manage their lymphedema so well they become convinced they no longer have it. All women who have had episodes of lymphedema should follow these guidelines and their doctor's instructions to avoid the return or worsening of lymphedema swelling.

Women who have had many lymph nodes removed and women who have had radiation therapy have a higher risk of developing lymphedema.

What is the lymph system?

Our bodies have a network of lymph nodes and lymph vessels that collect and carry watery, clear lymph fluid, much like veins collect blood from distant parts of the body (like the hands and arms) and carry it back to the heart. Lymph fluid has proteins, salts, and water, as well as white blood cells, which help fight infections. In the lymph vessels, one-way valves work with body muscles to help move the fluid through the body. Lymph nodes are small collections of tissue that work as filters for harmful substances and help us fight infection.



The lymph system in the upper body

Why do I need to know about lymphedema?

Some women who have been treated for breast cancer develop swelling or lymphedema of the arm, breast, and chest. Most women who have had breast cancer will not develop this side effect. The risk of lymphedema is higher for women whose breast cancer was treated with both surgery and radiation therapy. We also know that the risk of lymphedema goes up with the number of lymph nodes removed and is higher in women who are obese. Still, there's no way to predict who will develop this condition.

Here is what we know about lymphedema, the signs you can look for, steps you can take to lower your risk of getting it, and things you can do to try to keep it from getting worse. Talk to someone on your health care team about your lymphedema risk and what you can

do to lower it. There are things you can do to try to prevent lymphedema. And recognizing it early and starting treatment right away can help manage it.

Signs of lymphedema

Some signs of lymphedema:

- Swelling in the breast, chest, shoulder, arm, or hand
- Part of your body feels full or heavy
- Skin changes texture, feels tight or hard, or looks red
- New aching, tingling, or other discomfort in the area
- Less movement or flexibility in nearby joints, such as your shoulder, hand, or wrist
- Trouble fitting your arm into jacket or shirt sleeves
- Your bra doesn't fit the same
- Your ring, watch, and/or bracelet feels tight, but you haven't gained weight

Early on, the skin usually stays soft and raising your affected arm might relieve the swelling. But over time, the swollen area may become hot and red and the skin hard and stiff.

If you've had any type of breast surgery, lymph nodes removed, or radiation treatment, look at your upper body in front of a mirror. Compare both sides of your body and look for changes in size, shape, or skin color. Get to know your body and what's normal for you. This way you can spot changes and get treatment right away.

What to do after surgery or radiation to reduce swelling

Right after surgery, the incision (cut) in the breast and underarm area may swell. This swelling is usually short-term and slowly goes away over the next 6 to 12 weeks. Some women also have swelling in the affected arm, which may go away on its own. But arm swelling after breast surgery can mean a higher risk of lymphedema later. Talk to your doctor or nurse about what you should expect and what you should do. These tips may help ease the swelling:

- Use your affected arm as you normally would when combing your hair, bathing, dressing, and eating.

- Put your affected arm above the level of your heart 2 or 3 times a day and keep it there for 45 minutes. Lie down to do this, and fully support your arm. Place your arm up on pillows so that your hand is higher than your wrist and your elbow is a little higher than your shoulder.
- Exercise your affected arm while it's supported above the level of your heart by opening and closing your hand 15 to 25 times. Repeat this 3 to 4 times a day. This helps reduce swelling by pumping lymph fluid out of your arm through the undamaged lymph vessels.
- Talk to your doctor, nurse, or physical therapist before doing any exercises. Exercise is an important part of fitness, but you need time to heal after surgery and should follow the advice of your health care team.
- Keep in mind that radiation therapy after surgery may also cause some swelling in the arm, chest, and breast, especially toward the end of treatment. In most cases, this swelling will only last a short-time and will slowly go away. During and after radiation therapy, you should do simple stretching exercises each day to keep full movement in your chest, arm, and shoulder muscles. The tissue damage from radiation treatment continues over decades, so plan to make these simple stretching exercises a long-term part of your daily routine.

Recent studies are trying to find lymphedema early and treat it right away to help better control it. If you notice tingling or strange sensations in your arm after surgery, talk with your doctor, even if you haven't noticed swelling. If you feel uncomfortable, ask your doctor to refer you to a specialist who's an expert in managing lymphedema.

Some doctors are also measuring the arms before surgery, then re-measuring afterward so that swelling can be detected and treated before it becomes obvious. You can ask your doctor to take these measurements or refer you to a physical therapist to have this done. If possible, ask to be referred to a certified lymphedema therapist (CLT).

When to get help

Call your doctor, nurse, physical therapist, or lymphedema therapist if you notice any of the signs of lymphedema listed above or any of these changes:

- If any part of your affected arm, chest, breast, or underarm area (axilla) feels hot, looks red, or swells suddenly. These could be a sign of infection or a blood clot, and you might need treatment right away.
- If you have a temperature of 100.5°F or higher (taken by mouth) that's not related to a cold or flu
- If you have any new pain in the affected area with no known cause

For women at risk for lymphedema

At this time, there are no scientific studies to show that lymphedema can be prevented. Still, most experts say following these basic steps might lower your risk of lymphedema, delay its onset, or reduce its impact:

Get regular medical check-ups.

Regular check-ups should include screening for lymphedema. If you've been recording arm measurements, this may be part of the check-up. Talk to your health care team about how often you should be checked.

Don't avoid mammograms.

At this time, there's no link between mammograms and the start of or worsening of lymphedema. Mammograms are a key part of breast cancer follow-up and should not be avoided because of worries about lymphedema. If you do notice breast swelling or soreness after a mammogram, please talk to your doctor or lymphedema therapist.

Report changes.

After surgery, you will learn how your arm, chest, and breast normally feel. Any changes in size, color, temperature, feeling, or skin condition should be reported to your doctor right away.

Try to get to and/or stay at a healthy weight.

We know that obese women are at higher risk for lymphedema. Talk to your health care team about what a healthy weight is for you, and get their advice on how to get to or stay at that weight.

Exercise.

It's important to use your affected arm for normal, everyday activities to help you heal properly and regain strength. This includes doing things like brushing your hair and bathing. Using your muscles also helps drain lymph fluid from your arms.

Certain types of exercise can reduce your lymphedema risk, too. Exercise can also make lymphedema better. Avoiding exercise and allowing your arm to get out of shape may lead to lymphedema and episodes of swelling that are sometimes called flare-ups. That said, it's important to know that some kinds of exercise can increase your risk of lymphedema or make lymphedema worse if you already have it. Work with a well-trained fitness or health professional to design a program that starts at a low level of

intensity and progresses slowly enough to ensure that you are able to avoid the overuse that we know is bad for the lymph system.

If you've had surgery or radiation treatment, ask your doctor or nurse when you can start to exercise and what type of exercises you can do. But keep in mind that overuse, which can result in injury, has been linked with the start of lymphedema in some women. It's a good idea to follow these tips:

- Use your affected arm as normally as you can. Once you are fully healed, about 4 to 6 weeks after surgery or radiation treatment, you can begin to go back to the activities you did before your surgery. But check with your doctor first.
- Exercise regularly, but try not to over-tire your shoulder and arm. Before starting any exercises, talk with your doctor, nurse, or physical therapist. They can help you set goals and limits so that you can work at the level of activity that's right for you.
- If your arm starts to ache, lie down and raise it above the level of your heart.
- Avoid vigorous, repeated activities.
- Avoid heavy lifting or pulling.
- Use your unaffected arm or both arms as much as possible to carry heavy packages, groceries, handbags, or children.

Talk to your doctor or another health professional about exercise before starting any kind of work out.

Use of compression garments

Compression garments are fitted sleeves that can help control lymphedema. They can help prevent swelling and reduce it, too, by moving lymph fluid from the arm back into the body. Careful fitting is needed and you should follow your health care professional's advice on use and care of the garment.

Compression garments are most often used by women who already have lymphedema. But if you are at risk for lymphedema, you might want to use one to lower your risk in certain high-risk situations. For instance, lymphedema has been linked with air travel, possibly because of air pressure changes, but there are pros and cons to using a compression garment on long or frequent airplane flights. Ask your doctor or therapist if you should be fitted for a sleeve to wear during air travel. You might also want to discuss ways to safely raise your arm above the level of your heart and exercise it during long flights.

Do not use a poorly-fitting sleeve under any circumstances, as this may increase risk for or worsening of lymphedema.

You usually do not need a compression garment to prevent lymphedema during exercise. But if you've noticed swelling while exercising, talk to your doctor or therapist.

Try to avoid infection.

Your body responds to infection by sending extra fluid and white blood cells to fight the infection. If lymph nodes and vessels are missing or damaged, it's harder for your body to move this extra fluid, which can trigger or worsen lymphedema. Good hygiene and careful skin care may reduce the risk of lymphedema by helping you avoid infections. Follow these tips to help you care for the hand and arm on the side of your body that had surgery:

- Have your blood drawn, IVs, and shots done in your unaffected arm if you can. Also get flu shots and vaccinations in your unaffected arm or somewhere else, like the hip. Tell the doctor or nurse that you are at risk for lymphedema.
- Keep your hands and cuticles soft and moist by regularly using moisturizing lotion or cream. Push your cuticles back with a cuticle stick rather than cutting them with scissors.
- Keep your arm clean. Clean and protect any skin breaks caused by cuts, scratches, insect bites, hangnails, or torn cuticles. See “How to care for cuts, scratches, or burns” in the section called “Take care of yourself.”
- Wear protective gloves with sleeves when doing household chores that use harsh chemical cleansers or steel wool, when gardening or doing yard work, and when working with animals that scratch or bite.
- Wear a thimble when sewing to cut down on needle and pin pricks to your fingers.
- Be extra careful when shaving your underarms, and use a clean razor on clean skin.
- Use an insect repellent to avoid bug bites when outdoors. If you are stung by a bee on the affected arm, clean and put ice on the area and raise the arm. Keep it clean, and call your doctor or nurse if the sting shows any signs of infection.
- Protect yourself against falls, fractured bones, and serious burns.

Be aware of cellulitis.

Cellulitis is an infection in the tissues just under your skin. Signs of this problem include redness, warmth, fever, pain, and flu-like symptoms. Report this urgent medical problem to your doctor right away.

Cellulitis can lead to or worsen lymphedema. In fact, if it becomes a repeated problem, suppressive antibiotics may be used to keep it under control.

Try to avoid burns and extreme temperatures.

Like infections, burns can cause extra fluid to build up and cause swelling when lymph nodes have been removed or damaged. To avoid burns:

- Protect your chest, shoulders, and arms from sunburn. Use sunscreen labeled SPF 30 or higher, and try to stay out of the sun between the hours of 10 a.m. and 4 p.m., when the ultraviolet rays are strongest.
- Use oven mitts that cover your lower arms.
- Be careful when frying foods, boiling liquids, and removing food from a microwave oven.
- Avoid high heat, such as from hot tubs and saunas. If you use a heating pad or ice pack on the affected areas, limit the length of time you use it until you know how your body will respond. Both heat and cold can damage tissues and can increase fluid build-up. Some doctors may advise you to stay away from all sources of extreme temperatures.

Try to avoid constriction.

Constriction or squeezing of the arm may increase the pressure in nearby blood vessels. This may lead to increased fluid and swelling (much like water building up behind a dam). Some women have linked this with the start of lymphedema. Tips include:

- Wear loose jewelry, clothing, bras, and gloves. Avoid anything that fits too tightly or puts pressure around your chest, arm, or wrist. Be sure compression garments fit well and are worn properly. Clothing and compression garments should be supportive and have smooth, even compression.
- Do not use shoulder straps when carrying briefcases and purses.
- Wear a loose-fitting bra with padded straps that don't dig into your shoulder. Make sure underwires don't put pressure on your breast or chest. After a mastectomy, use a lightweight prosthesis (breast form). A heavy prosthesis may put too much pressure on the area.
- Have your blood pressure taken on the unaffected arm. If both arms are affected, blood pressure can be taken on your thigh. Or, you can ask that blood pressure be measured by someone using a hand pump and stethoscope rather than using a machine; the machines often use high pressures for a longer time.

For women who have lymphedema

If you develop lymphedema, there are treatments to reduce the swelling, keep it from getting worse, and decrease the risk of infection. The treatment is prescribed by your doctor and should be given by an experienced therapist. Be sure to check your health insurance to make sure the treatment is covered.

Mild lymphedema should be treated by a physical therapist or other health care professional who has had special training.

Moderate or severe lymphedema is most often treated by a therapist with special training and expertise who will help you with skin care, massage, special bandaging, exercises, and fitting for a compression sleeve. This is sometimes known as *complex decongestive therapy*, or CDT. *Manual lymphatic drainage*, or MLD, is the type of massage used as part of CDT to manage lymphedema. The therapist will also teach you things like how to care for the lymphedema at home and how and when to wear the compression sleeve.

Although most insurance companies will pay for lymphedema treatment, some do not cover the cost of compression garments and dressings. Check with your insurance company about coverage for these therapies.

Seeking and getting treatment early should lead to a shorter course of treatment to control your lymphedema. Again, it's important to notice changes right away and get help as soon as possible.

Lymphedema can and should be treated right away to keep it from getting worse.

Take care of yourself.

It's important to take good care of your skin – especially in the affected area. Keep your skin clean and dry. Use moisturizers regularly to keep your skin from cracking.

How to care for cuts, scratches, or burns

- Wash the area with soap and water.
- Put an over-the-counter antibiotic cream or ointment on the area. Check with your doctor, nurse, or pharmacist if you're not sure what to use.
- Cover with a clean, dry gauze or bandage. Keep the area clean and covered until it heals. Change the dressing each day and if it gets wet.

- For burns, apply a cold pack or cold water for at least 15 minutes, then wash with soap and water and put on a clean, dry dressing.
- Check every day for early signs of infection: pus, rash, red blotches, swelling, increased heat, tenderness, chills, or fever.
- Call your doctor right away if you think you have an infection.

Caring for your whole body

Taking care of your whole body is also important. Here are some good ways to stay as healthy as possible:

- Get to and stay at a healthy weight.
- Eat more servings of vegetables and fruits each day (try for at least 2½ cups total).
- Choose whole-grain foods instead of white flour and sugars.
- Cut back on red meat and processed meats like hot dogs, bologna, and bacon.
- If you drink alcohol, limit yourself to 1 drink a day.
- Don't forget to get some type of regular exercise. This is a key part of lymphedema management. Talk to your health care team about the types of exercise that are best for you. The challenge with exercise recommendations for women with and at risk for lymphedema is that there are risks to both exercising and NOT exercising. This situation is much like exercising after a heart attack: Not exercising allows for further deconditioning (which is bad), but over-exercising may cause harm. Trained health professionals such as fitness trainers and physical and occupational therapists can help you learn how to exercise safely.
- Try to reduce the stress in your life and get enough sleep.

You also need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, places of worship or spiritual groups, online support communities, or one-on-one counselors. You may want to get support from others with lymphedema. It helps to talk to people who understand what you're going through. Call us or contact the National Lymphedema Network (see the "To learn more" section) to find support groups in your area.

You can't change the fact that you are at risk for lymphedema. What you can change is how you live your life – taking good care of yourself, making healthy choices, and doing what you can to make your body and your mind feel as good as possible.

Take the quiz.

The following is a self-quiz to help you remember some of the key points covered here. Try taking the quiz, then look at the answers. If you have any questions, or something isn't clear, talk to your doctor or nurse.

1. To help prevent and control long-term swelling, you should remember the hand and arm precautions:

- a. Forever
- b. Until you feel fine
- c. Until your doctor says you have developed new lymph pathways
- d. For 6 months after surgery and/or radiation
- e. For 6 weeks after surgery and/or radiation

2. To help prevent infection in the affected arm:

- a. Cut your cuticles every week.
- b. Wear gloves when working with hot or sharp objects.
- c. Do not have blood drawn from the affected arm.
- d. Stay out of bright sunlight.
- e. b and c only

3. If swelling appears in the affected arm or hand soon after surgery:

- a. Raise the arm for 45 minutes.
- b. Call your doctor or nurse right away.
- c. Raise and support your hand or arm above the level of your heart, then open and close your hand 15 to 25 times.
- d. a and c only
- e. a, b, and c

4. Call your doctor or nurse:

- a. If the affected breast, hand, arm, or underarm (axilla) feels hot or is red or swollen
- b. If you have a temperature over 100.5° F
- c. If you want to start shaving your underarm
- d. a and b only
- e. a, b, and c

Answers

1. a – Forever. Remember these precautions to help protect your arm and reduce your risk of ever getting lymphedema.

2. e – b and c only. Wear gloves when working with hot or sharp objects. Do not have blood drawn or have your blood pressure taken from the affected arm. Use a sunblock (SPF 30 or higher) to prevent sunburn. Do not cut your cuticles; use lotion and a cuticle stick instead.

3. e – a, b, and c. Call your doctor or nurse. You can also raise and support your arm for 45 minutes and open and close your hand 15 to 25 times. Repeat this 2 to 3 times.

4. d – a and b only. Call your doctor or nurse if you have symptoms that might mean an infection, such as if the affected arm or underarm feels hot or is red or swollen, or if you have a fever that's not related to a cold or flu. It's OK to shave your underarm. Just be extra careful to not cut yourself, and be sure the skin and the razor are clean.

To learn more about lymphedema

National organizations and Web sites*

Along with your American Cancer Society, other sources of information and support include:

Lymphology Association of North America (LANA)

Web site: www.clt-lana.org

Web site lists therapists, nurses, and doctors who specialize in treating lymphedema

National Lymphedema Network (NLN)

Toll-free number: 1-800-541-3259

Web site: www.lymphnet.org

Has patient information on reducing risk and managing lymphedema, offers support and a way to search for professionals who work with people who have lymphedema

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

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