What is lymphedema?

Lymphedema (limf-uh-DEE-muh) is a build-up of lymph fluid in the fatty tissues just under your skin.
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 contains 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 fight infection.

What causes lymphedema?

During surgery for breast cancer, the doctor might take out lymph nodes from under the arm 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 go through and are wrapped around the nodes.

Removing lymph nodes and vessels changes the flow of lymph fluid in that part of the body. With breast cancer, it makes it harder for fluid in the chest, breast, and arm to flow out of these areas. If the remaining lymph vessels can’t drain enough fluid from these areas, the fluid builds up and causes swelling, or lymphedema.

Radiation treatment to the underarm lymph nodes can also affect lymph fluid flow in the arm, chest, and breast area by causing scarring and damage. This further increases the risk of lymphedema.

In most cases, lymphedema develops slowly over time. The swelling can range from mild to severe. It can start soon after surgery and/or radiation treatment. But it can also start months or even many years later.

**Who gets lymphedema?**

Any woman whose lymph nodes are affected by breast cancer treatment can get lymphedema. But women who have many lymph nodes removed and women who have had radiation therapy for breast cancer have a higher risk of lymphedema.

Doctors still don’t 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 have 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 procedures like sentinel lymph node biopsy, which allows the surgeon to remove fewer lymph nodes.

- Studies are looking at ways to find the lymph nodes that drain the arm before surgery so they can be saved when possible. This is called axillary reverse mapping.

**Why do I need to know about lymphedema?**

There’s still a lot to be learned about lymphedema, and there’s no way to predict who will develop it. But there are things you can do to care for your arm and breast area to reduce your chances of getting it.
Once lymphedema has started, it can’t be cured. Still, 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.

Here you will find 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 cancer care team about your lymphedema risk and what you can do to lower your risk.

All women who have had episodes of lymphedema should follow the guidelines shared here and their cancer care team’s instructions to avoid the return or worsening of lymphedema.

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

**Signs and symptoms of lymphedema**

Signs and symptoms of lymphedema can include:

- Swelling in the breast, chest, shoulder, arm, or hand
- Part of your body feeling full or heavy
- Skin changing texture, feeling tight or hard, or looking 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 not fitting as well as it used to
- Your ring, watch, and/or bracelet feeling tight, and 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 help reduce swelling

Right after surgery, the incision (cut) in the breast and underarm area may swell. This swelling usually goes away slowly 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 cancer 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 can continue over many years, so plan to make these simple stretching exercises a long-term part of your daily routine.

If you notice tingling or strange sensations in your arm after surgery or radiation, 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 measure the arms before surgery, then re-measure 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 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, it’s not clear if 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 checking for lymphedema. If you’ve been recording arm measurements, this may be part of the check-up. Talk to your cancer 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, be sure to talk to your doctor or lymphedema therapist.

**Report any changes.**

After surgery, you’ll learn how your arm, chest, and breast normally feel. Tell your cancer care team about any changes in size, color, temperature, feeling, or skin condition 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 cancer care team about what a healthy weight is for you. 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 helps drain lymph fluid from your arms. It also helps keep your muscles flexible and helps reduce scarring.

Certain types of exercise can help reduce your lymphedema risk, too. In fact, avoiding exercise and allowing your arm to get out of shape may lead to lymphedema and bouts 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 trained fitness or health professional to design an exercise plan that starts at a low level of intensity and progresses slowly to ensure that you avoid overuse, which is bad for the lymph system.

If you’ve had surgery or radiation, ask your cancer care team when you can start to exercise and what type of exercises you can do. But keep in mind that overuse, which can lead to injury, has been linked to 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, you can begin to go back to the activities you did before your surgery. But check with your cancer care team 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 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 to carry heavy packages, groceries, handbags, or children.
Use of compression garments

Compression garments are fitted sleeves that can help control lymphedema. They can help prevent or reduce swelling 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’re at risk for lymphedema, you might want to use one to help lower your risk in certain 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. This may increase your risk for or worsen lymphedema.

You usually don’t 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 your risk of lymphedema by helping you avoid infections. Follow these tips to care for the hand and arm on the side of your body that had surgery or radiation:

- 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’re 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 might 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 help prevent bug bites when outdoors. If you’re bit or stung on the affected arm, clean and put ice on the area and raise the arm. Keep it clean, and call your cancer care team if the bite or sting shows any signs of infection.

• Do what you can to protect yourself against falls and fractured bones.

Be aware of cellulitis.

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

Cellulitis can lead to or worsen lymphedema. In fact, if it becomes a repeated problem, antibiotics may be needed 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. Cover these areas with tightly woven clothing, or use a broad-spectrum sunscreen labeled SPF 30 or higher. Try to stay out of the direct sun between the hours of 10 a.m. and 4 p.m., when the ultraviolet (UV) 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 responds. Both heat and cold can damage tissues and 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 can 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 might put too much pressure on the area.

- Have your blood pressure taken on the unaffected arm, if possible. 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

Check the tips in the “For women at risk for lymphedema” section. They can be useful to women with lymphedema, too.

When you develop lymphedema, there are treatments to help 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 garment. 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 garment.

Although most insurance companies will pay for lymphedema treatment, some don’t cover the cost of compression garments and dressings. Check with your health insurance company.

Seeking and getting treatment for lymphedema early should lead to a shorter course of treatment to control it. 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, redness, swelling, increased heat, tenderness, chills, or fever.
- Call your cancer care team 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 vegetables and fruits each day. (Try for at least 2½ cups a day.)

• Choose whole-grain foods instead of those made with white flours 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 cancer care team about the best types of exercise 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’re 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 cancer care team.

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 cancer care team 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 cancer care team:
   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 help 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 broad-
   spectrum sunscreen (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 cancer care team. 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 cancer care team 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 websites*

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

**Lymphology Association of North America (LANA)**
Website: www.clt-lana.org
Website lists LANA therapists who specialize in treating lymphedema

**National Lymphedema Network (NLN)**
Toll-free number: 1-800-541-3259
Website: www.lymphnet.org
Has patient information on reducing risk and managing lymphedema, offers a pen pal/net pal program, conferences, support group info, and a way to search for professionals who work with people who have lymphedema

**Lymphatic Education & Research Network (LE&RN)**
Phone number: 516-625-9675
Website: www.lymphaticnetwork.org
Website has information on lymphedema and an Ask the Experts section where you can get specific questions answered. Also offers monthly live-stream webcasts on lymphedema research and treatment, as well as regular newsletters on advances in the field.

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

References


