



Understanding Lymphedema – For Cancers Other Than Breast Cancer

What is lymphedema?

Lymphedema (limf-uh-**dee**-muh) is a build-up of lymph (limf) fluid in the fatty tissues just under the skin. This build-up causes swelling (or edema [uh-**dee**-muh]), most often in the arms or legs. Lymphedema can also affect the face, neck, abdomen (belly), and genitals – depending on the part of the body that was treated. There are 2 types of lymphedema:

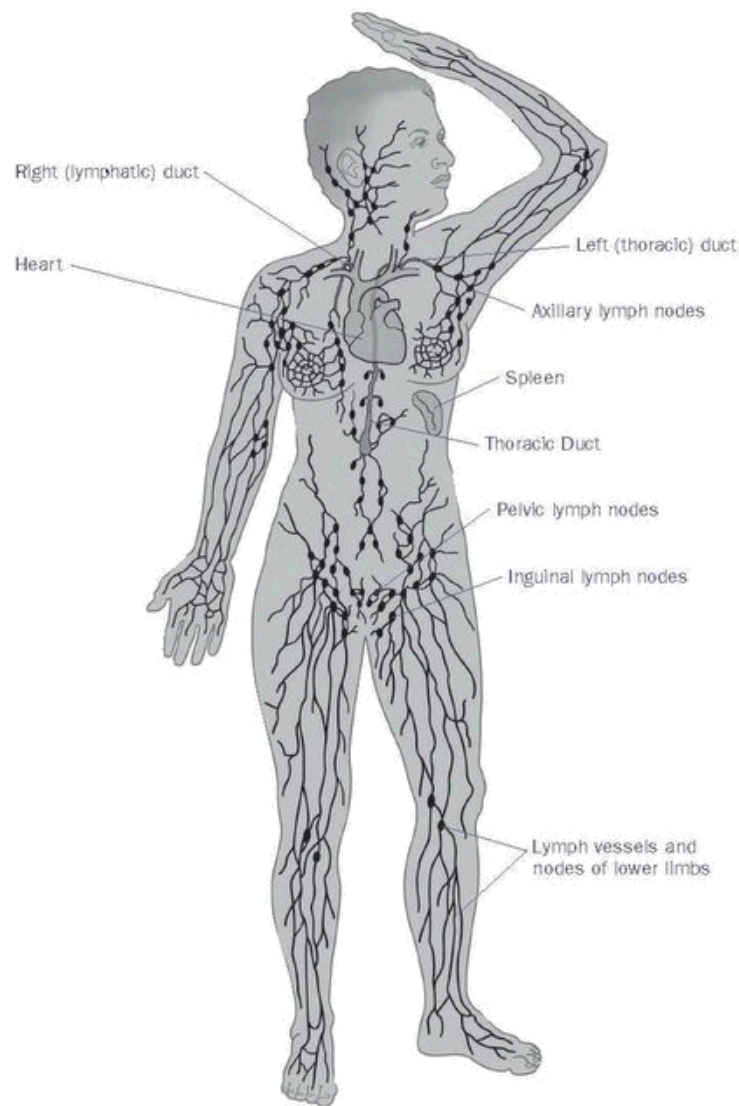
- **Primary lymphedema** occurs in people born with genes that put them at an increased risk of developing lymphedema. This lymphedema is caused by lymph nodes or vessels that are missing or not working the way they should. This type of lymphedema is rare.
- **Secondary lymphedema** is a result of cancer, cancer treatments, tumors, diseases, or anything that changes or damages the normal, healthy lymph system.

The rest of the information here is about secondary lymphedema – what we know about it, 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. Once chronic lymphedema has started, it cannot be cured. But early and careful management can reduce symptoms and help keep it from getting worse.

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 and carry blood from distant parts of the body (like the arms and legs) 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

Signs of lymphedema

Some signs of lymphedema:

- Swelling
- Part of your body, like your arm, leg, belly, or genitals, 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, like your hand, wrist, or ankle, or your eyelid(s) or lips
- Trouble fitting into clothes in one area, such as a jacket sleeve, pant leg, or shoe being tight

- Collars, rings, watches, and/or bracelets feel tight even though you haven't gained weight

At first, the skin usually stays soft and raising the affected body part might relieve the swelling. But over time, the swollen area may become hot and red and the skin hard and stiff.

If you have had lymph nodes removed or radiation treatment, look closely at your 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. Let your doctor, nurse, or lymphedema therapist know if you notice any of the signs listed above.

Some doctors measure the affected body part (like a leg or arm) 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 does lymphedema develop?

Just after surgery: short-term lymphedema

Lymphedema can start right after surgery. This is called *temporary lymphedema*. It's usually mild and goes away in 1 to 2 weeks. It can also happen later, about 6 to 8 weeks after surgery or radiation. Again, this type of lymphedema usually goes away in a few weeks, but if it happens you should tell your doctor about it right away. The affected area may look red and feel hot, which could also be a sign of blood clot, infection, or other problem. If nothing else is going on, it might be treated by raising the arm or leg and taking medicines to reduce inflammation. Studies of arm swelling after breast surgery suggest that this early swelling could mean a higher risk of lymphedema later. It's unclear at this time whether this might also apply to other parts of the body.

Months or years after cancer treatment: chronic lymphedema

This form of lymphedema develops slowly over time. It may show up many months or even years after cancer treatment. The swelling can range from mild to severe. The lymph fluid that collects in the skin and underlying tissues can be very uncomfortable. It can keep nutrients from reaching the cells, interfere with wound healing, and lead to infections. Lymphedema can be a long-term problem, but there are ways to manage it.

We still have a lot to learn about lymphedema, but there are things you can do to take care of yourself, help lower your risk of getting lymphedema, and recognize it early so you can start treatment right away.

When to get help

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

- If any part of your body feels hot, looks red, has red blotches or streaks, gets tender (sore when touched), 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

What causes lymphedema?

Any change in the structure of the lymph system puts a person at risk for lymphedema.

Surgery: During surgery for cancer the doctor may take out lymph nodes near the tumor to see if the cancer has spread. Lymph vessels may also be removed because they are wrapped around the lymph nodes. Taking out lymph nodes and vessels makes it harder for the fluid in the arms, legs, or other body parts to flow to the chest where it can get back into the bloodstream. If the remaining lymph vessels cannot remove enough of the fluid in the area, the excess fluid builds up and causes swelling.

Radiation: Radiation treatment can affect the flow of lymph fluid by scarring the lymph nodes and vessels; this increases the risk for lymphedema, too.

Cancer: Sometimes, a tumor itself can block part of the lymph system and cause lymphedema.

Infection: Infections that restrict lymph flow can cause lymphedema.

Who gets lymphedema?

Doctors do not fully understand why some patients are more likely to have problems with fluid build-up than others. People who have many lymph nodes removed and/or radiation therapy have a higher risk of chronic lymphedema. But there's no way to predict who will develop it.

Lymphedema can become a problem after surgery or radiation treatment for any type of cancer. It's often linked to treatments for

- Breast cancer
- Prostate cancer
- Pelvic area cancers (such as bladder, testicular, uterine, vulvar, or cervical cancer)
- Lymphoma
- Melanoma

Lymphedema is seen more often in the arms or legs, but it can happen in other areas, too. If lymphedema occurs after breast cancer treatment, it can affect the breast, chest, and underarm, as well as the arm closest to the surgery. After cancer in the abdomen (belly) or pelvis has been treated, lymphedema may appear as swelling of the abdomen (belly), genitals, or one or both legs. Treatment of tumors in the head and neck area has been linked with lymphedema in the face, mouth, eyes, and neck.

For people 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 measurements of the affected part of your body, this may be part of the check-up. Talk to your health care team about how often you should be checked.

Report changes.

After surgery and/or radiation, you will learn how the affected part of your body normally feels. 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 people 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 the part of your body that's been affected by cancer for normal, everyday activities to help you heal properly and regain strength. Using your muscles also helps the lymph fluid drain like it should.

Certain types of exercise can reduce your lymphedema risk, too, and some exercises can make lymphedema better after it starts. 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. Avoiding exercise and allowing your body to get out of shape may lead to lymphedema and episodes of swelling that are sometimes called flare-ups.

But keep in mind that some kinds of exercise can increase your risk of lymphedema or make lymphedema worse if you already have it. Overuse, which can result in injury, has also been linked with the start of lymphedema in some people. Work with a well-trained fitness or health professional to design a program that's right for you and starts at a low level of intensity and progresses slowly to avoid overuse.

Follow these tips for exercising safely:

- Use your affected body part 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 yourself. 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 the affected part of your body starts to ache or swell, lie down and raise it above the level of your heart.
- Avoid repetitive overuse of the affected body part. Sudden increases in how long or hard you work out might trigger or worsen lymphedema.
- Any exercise program should be started gradually, increased cautiously, and stopped if you have pain, more swelling, or other discomfort. Talk with your doctor if you have any of these problems. If they continue, ask about being referred to a lymphedema specialist.

Use of compression garments

Compression garments are fitted sleeves or stockings that can help control lymphedema. They can help prevent and reduce swelling by moving lymph fluid from the arm or leg 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 people 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 flights. Ask your doctor or therapist if you should be fitted for a garment to wear during air travel.

Do not use a poorly-fitting compression garment under any circumstances, as this may increase risk for lymphedema or make it worse if you already have 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 infections, burns, and injuries.

Your body responds to infection, burn, or injury by sending extra fluid and white blood cells to the area. 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.

Some basic precautions, good hygiene and careful skin care may reduce the risk of lymphedema by helping you avoid infections, burns, and injuries. Follow these tips to help you care for the part of your body that had surgery and/or radiation:

- Keep the affected area clean. Careful skin care can help you prevent infections.
- Keep your hands, feet, and cuticles soft and moist by regularly using moisturizing lotion or cream. This will help keep your skin from chapping or cracking. Push your cuticles back with a cuticle stick while they are soft (after a bath) rather than cutting them with scissors. Try not to pick at or bite your cuticles.

- Clean and protect any openings in your skin caused by cuts, scrapes, scratches, bug bites, hangnails, or torn cuticles. See “How to care for cuts, scratches, or burns” in the section “Take care of yourself.”
- Watch for early signs of infection, like pus coming from a cut or scrape, rash, red blotches or streaks, swelling, increased heat, tenderness, chills, or fever. Call your doctor right away if you think you have an infection.
- Be extra careful when shaving, and use a clean razor on clean skin.
- Use an insect repellent to avoid bug bites when outdoors. If a bee stings you in the affected area, clean and raise the limb, put ice on the sting, and call your doctor if there are signs of infection (see above).
- Avoid activities that irritate or chap your skin.
- Protect your body, especially treated areas, from sunburn. Use a broad spectrum sunscreen that is labeled SPF 30 or higher, and try to stay out of the sun between 10 a.m. and 4 p.m.
- Your affected limb might not sense hot or cold as well as it did in the past. Test bath water temperatures with an unaffected limb.
- Avoid extreme temperature changes, such as heat from hot tubs and saunas. If you use a heating pad or ice pack on the affected area, 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.
- 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. See the section “Take care of yourself” for ways to help prevent infection.

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.

If your arm is affected

- Whenever possible, have your blood drawn, IVs, and shots given in your unaffected arm. Get flu shots and vaccinations in your unaffected arm or somewhere else. Let all your health care providers know that you are at risk for lymphedema.
- Wear protective gloves with sleeves when doing household chores using harsh chemical cleansers or steel wool, when gardening or doing yard work, and when working with animals that could scratch or bite.
- Wear a thimble when sewing to cut down on needle and pin pricks.
- Use oven mitts that cover your arms instead of hot pads. Be careful when frying foods, boiling liquids, and removing food from a microwave oven.

- Keep pets' claws trimmed to avoid getting scratched.

If your legs are affected

- Always wear well-fitting, closed shoes instead of sandals or slippers. Do not go barefoot.
- Keep your feet clean and dry. Wear soft protective socks (cotton or padded types).
- Dry the creases between your toes after bathing.
- Cut toenails straight across to help prevent ingrown toenails.

Try to avoid pressure or constriction.

Constriction or squeezing of the affected body part 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 people have linked this to the start of lymphedema. Here are some tips to help you with this:

If your arm is affected

- Wear loose jewelry, clothing, and gloves. Do not wear anything that forms a snug band around your 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 do not dig into your shoulder.
- 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.

If your legs are affected

- Avoid socks, stockings, undergarments, or pants with tight elastic bands.
- Wear shoes that fit well.
- Try not to stand or sit in one place for too long (more than 30 minutes). Do not cross your legs when sitting.
- Most people with leg lymphedema benefit from wearing a compression stocking when up and walking around. A compression stocking can help squeeze the lymph fluid through the remaining vessels before it builds up. The stocking must be well fitted to apply the right pressure while avoiding too much tightness near the top of the stocking. Ask your doctor or physical therapist if you should be fitted for a compression stocking.

For people who have lymphedema

If you develop lymphedema, your doctor can prescribe treatments to reduce the swelling, keep it from getting worse, and decrease the risk of infection.

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

Moderate or severe lymphedema is most often treated by a lymphedema 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.

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

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

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 right away 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 important, too. 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 for women and 2 drinks a day for men.
- Talk to your health care team about the types of exercise that are best for you..
- Try to reduce the stress in your life and get enough sleep.

Regular exercise is a key part of lymphedema management. But remember that for people with and at risk for lymphedema, 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.

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 about cancer and lymphedema" section) to find support groups in your area.

You can't change the fact that you have or 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.

To learn more about cancer and lymphedema

More information from your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our Web site, www.cancer.org.

Coping With Cancer in Everyday Life (also in Spanish)

Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families (also in Spanish)

Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions

Understanding Radiation Therapy: A Guide for Patients and Families (also in Spanish)

Books

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at www.cancer.org/bookstore to find out about costs or to place an order.

National organizations and Web sites*

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

American Physical Therapy Association (APTA)

Toll-free number: 1-800-999-2782

TTY: 703-683-6748

Web site: www.apta.org

Web site has a list of physical therapists who work with people with cancer (oncology physical therapists); information on how PT can help lymphedema can be found at www.oncologypt.org

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.*

No matter who you are, we can help. Contact us anytime, day or night, for cancer-related information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

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