

# Lymphedema



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## Dear Friend:

You may be reading this guide before your breast cancer therapy begins or while you are in the middle of it, or you could be years past your breast cancer experience and just learning that you have developed a side effect. After giving so much time and thought to choosing the best treatment plan for you, it can be distressing to learn about lymphedema, a health problem that can arise from breast cancer treatment.

Our *Guide to Understanding Lymphedema* seeks to empower you with information about how lymphedema develops, what your risks are, which signs to watch for and what to do should you develop it. By treating lymphedema early, you can keep it from turning into a serious problem.

At Living Beyond Breast Cancer, we encourage you to get answers to all your questions. We're here for guidance and support — just contact our **Breast Cancer Helpline** at [lbbc.org/helpline](https://lbbc.org/helpline) or call toll-free at **(888) 753-5222** — whenever you need us.

Warmly,

A handwritten signature in blue ink, appearing to read 'Jean A. Sachs'. The signature is fluid and cursive, with a large initial 'J'.

Jean A. Sachs, MSS, MLSP  
Chief Executive Officer



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All people pictured in this guide are LBBC volunteers whose lives have been affected by breast cancer. We thank them for sharing their experiences.

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# Looking at Lymphedema

When you hear you need breast cancer treatment, your immediate concern is likely getting the best therapy. Your healthcare providers are focused on that same goal. What might be overlooked is a discussion about a condition called **lymphedema** that is a side effect of some breast cancer treatments.

Lymphedema happens when lymph fluid builds up in the hand, arm, breast, chest wall or under the arm on the side where you have cancer, resulting in swelling and other possible symptoms. Lymphedema can occur any time after treatment — even many years later. As fluid builds up and the area swells, it can cause pain, reduced movement, serious infections, emotional upset and reduced quality of life.

Researchers believe lymphedema is largely unrecognized and underdiagnosed. Studies show that between 5 and 50 percent of women treated for breast cancer develop the condition, depending on the treatment they receive.

Swelling can be lessened with early and proper detection, skilled therapy and ongoing self-care. Even if swelling goes away, lymphedema is a long-term side effect and remains a health concern for the rest of your life. But with proper treatment, it is possible to manage lymphedema well and move forward with your life.

# How Breast Cancer Treatment Can Lead to Lymphedema

Just under your skin, above your muscles, lies your **lymphatic system**. It's a series of tiny, thin tubes called **lymph vessels** that carry a nutrient-rich fluid, called **lymph**. The vessels travel through a web of **lymph nodes**; small, round organs that store white blood cells and filter bacteria and waste. Lymph fluid helps your body fight infection and then drains to other parts of your body. Your lymph system also removes fluid that leaks out of blood vessels, returning it to the system that handles your heart and blood.

To stay healthy, lymph fluid must keep moving. When lymph nodes are removed or hurt because of surgery or radiation, scar tissue can form and keep fluid from draining. At first, the tissue may feel firm and thick, but as fluid backs up, swelling and inflammation set in. If left untreated, the protein-filled fluid increases the risk for infection and more swelling.

Surgery can cut through the lymphatic channels, breaking up the pathways where lymph travels. Your risk for lymphedema after surgery depends on

- the type of breast cancer surgery you had
- the location and number of lymph nodes removed
- the way your body drains the fluid after surgery
- the way your body heals afterward

## Surgery

Surgery in the armpit, or **axillary**, region removes lower lymph nodes where the breast and underarm tissue meet. Higher lymph nodes in the underarm area may also be removed.



An **axillary lymph node dissection** removes many nodes in the lower to mid-upper underarm. A **sentinel lymph node biopsy** removes only the main nodes to which the breast lymphatics drain, typically one to three nodes in your lower armpit. Lymphedema can develop after sentinel lymph node biopsy, but it happens at a lower rate than with an axillary lymph node dissection. Your healthcare team will recommend which surgery is best for you.

You are at risk for lymphedema on the side where lymph nodes were removed. If you have a healthy breast removed as part of a **bilateral mastectomy**, you are not at risk for lymphedema on the healthy breast's side.

## Radiation Therapy

**Radiation therapy** is the use of high-energy x-rays to kill cancer cells that may still be in the area where the tumor was removed. It can increase the risk for developing lymphedema.

Radiation can cause scarring, or **fibrosis**, that prevents lymph flow. The wider the area of the breast radiated and the more of the underarm the radiation reaches, the greater the lymphedema risk. Radiation therapy that is given after the breast is removed or reconstructed can lead to lymphedema, especially if the lymph node area also is radiated.



## Who Gets Lymphedema?

Developing lymphedema is not your fault. We do not understand why one person gets lymphedema after breast cancer treatment while another, who has the same treatment, does not. If you have concerns about your risk, discuss them with your healthcare team. Worrying about lymphedema risk should not keep you from getting the treatment you need.

People who develop lymphedema tend to share certain traits, but having those traits does not mean you will get lymphedema. Lymphedema is linked to

- having more than 10 lymph nodes removed
- having multiple lymph nodes with cancer
- having radiation therapy
- getting an infection on the side of your body that had surgery
- overuse or trauma to the hand or arm on the affected side
- being a younger age at cancer diagnosis
- being overweight or obese
- gaining weight after treatment
- certain chemotherapy treatments, such as the **taxanes**, medicines that are used to prevent tumor growth by stopping cell division

Race does not increase risk. Research also shows that women who exercise regularly, learn about lymphedema before treatment and follow self-care advice develop it less often.

## 10 KEY TERMS TO KNOW

- 1 Axillary lymph node dissection.** Surgery to check for cancer in many of the lymph nodes in the armpit.
- 2 Cellulitis.** Infection and swelling that causes skin to be warm, red and tender; may also produce fever, chills, swollen lymph nodes or blisters.
- 3 Certified lymphedema therapist.** A trained professional, often a physical therapist, occupational therapist or nurse, who has passed a lymphedema certification course.
- 4 Complete decongestive therapy (CDT).** Treatment to manage lymphedema through a specialized type of gentle massage called manual lymphatic drainage, compression bandages, skin care and exercise.
- 5 Compression bandages and garments.** Short-stretch (low elasticity) bandages (not ACE bandages) wrapped around swollen areas after CDT to support and stimulate the lymphatic system, reducing swelling. Compression garments (sleeves, fingerless gloves or gauntlets, vests or bras) are used to treat lymphedema and must be well-fitted and prescribed by your healthcare provider or they can worsen the condition.

- 6 Lymph node.** Small round organ in the lymphatic system that works to filter bacteria and waste from the body.
- 7 Lymph vessel.** Thin tube that transports lymph and white blood cells throughout your body.
- 8 Lymphedema.** Condition in which excess fluid, called lymph, collects in tissues and causes swelling.
- 9 Manual lymphatic drainage (MLD).** Specialized hands-on skin manipulation, or massage-like stretching of the skin, sometimes called lymphatic massage, that moves lymph from affected area to elsewhere in the body for recirculation.
- 10 Sentinel lymph node biopsy.** Surgery that removes only the main lymph nodes to which the breast lymphatics drain, typically one to three nodes in your lower armpit.







# Know the Early Signs

It's important to seek medical advice from your health-care team at the first sign or symptom of lymphedema. The condition may develop slowly over time or more suddenly if you have an injury or infection in your arm. Early diagnosis and getting treatment started quickly has shown to greatly improve lymphedema outcomes.

You might notice changes in how your skin feels or moves before anyone else, including your provider, sees swelling. Speak up about any change you feel. Before swelling can be seen, you may feel an achiness, heaviness, tingling or increased warmth in your limb or hand. Monitor the tissue texture and skin on the side where you had surgery or radiation and compare it to the limb or hand on the opposite side. Ask yourself, "Are the veins or tendons on one hand harder to see than they used to be?" "Can I see valleys between my knuckles?" "Do my clothes or jewelry fit tighter on the side of the cancer?"

Swelling might occur during the day and go away at night or start and then go away when you elevate the swollen area. Bring these symptoms to your healthcare team if they persist. They could be signs of lymphedema.

Right after breast cancer surgery or radiation, you may have swelling, called **edema**, which is not the same as lymphedema. But that should be evaluated by your healthcare team. Take any concerns to them right away.



## Lymphedema Professionals

If lymphedema is the cause of the swelling, it is important to see a special therapist who can reduce the swelling and other symptoms as well as teach you ongoing care. Your cancer care team can make a recommendation. Some things to know:

- The Lymphology Association of North America (LANA) certifies therapists in complete decongestive therapy (see page 23) using national standards. Therapists may also be certified by the program that trained them. Your healthcare provider may have suggestions, too.
- Certified providers are often physical therapists or occupational therapists, as well as nurses, doctors or massage therapists. When choosing lymphedema therapists, ask about their training.
- Insurance coverage of lymphedema treatment can vary. Be sure to check whether their services are reimbursed by your health insurance plan.







# Taking Control of Lymphedema Risk

If breast cancer surgery or radiation involved your lymph nodes, there is no surefire way to prevent lymphedema. You can lower your risk or lessen the severity of lymphedema by paying attention to changes on your treated side, taking a few precautions and getting medical attention quickly if signs occur. It helps to see a lymphedema professional to talk about your personal risk.

Trauma or stress to the arm or hand on the treated side and minor injuries like scrapes, burns, bites or infections seem to trigger lymphedema. So might too much heat or cold. If you develop an infection, it is important to see a doctor quickly. Lymphedema also may occur on its own.

Measuring the arm helps detect lymphedema. Some facilities take baseline measurements before treatment and measure your arms regularly afterward. If there is a change in size, you can start treatment quickly.

Some techniques used to measure the volume and size of your arm include:

- **Circumference measurements**, which use a tape measure to find the distance around your arm. This is the most common method. Your provider will measure your arms from your hand to the armpit at different places. These places will be the same every time your arms are measured.
  - Any change in circumference of more than 2 centimeters, at any place in the affected arm, may suggest lymphedema.
- **Bioimpedance**, which passes low-dose electricity through the arm to see if you have extra fluid on the

side where you had cancer. The electricity is about the same as you would get during an electrocardiogram, or EKG, a common test used to monitor heart health. Bioimpedance involves a provider placing electrodes, which conduct electricity, on each wrist and your right foot. Cables are attached to each site for a few minutes. Bioimpedance does not hurt. If more fluid is found on the affected side than on the unaffected side, you may have lymphedema.

- If you have implanted metal in your body, such as a pacemaker or defibrillator, you cannot be measured with bioimpedance.

● **Perometry**, which passes signals through your arm to measure the volume of fluid. This method uses a machine called a **perometer**. You will sit or stand beside it and stretch your arm over a table as a square frame passes over your arm. After measuring both arms, the perometer compares the volume of fluid in milliliters between your two arms.

- This test is best given before lymph node surgery and every 3 months after. It is available at limited facilities and through research studies.

● **Water displacement**, in which each arm is placed in water and the amount of water that is displaced, or spilled, is measured. If one arm causes more water to spill than the other, you may have lymphedema. Because it can be messy, this method is used less often than other methods.

Some doctors use special x-rays to see lymph flow to diagnose lymphedema. Others look at the area on a **CT** (computed tomography, also called CAT) **scan** or **MRI** (magnetic resonance imaging).

Some facilities will monitor your arm circumference for months to years after treatment. If you have questions about how to measure your arm on your own, ask your oncologist or oncology nurse.

If the circumference has increased by more than 2 centimeters, a lymphedema therapist should check your arm. If you see any signs or symptoms of lymphedema, contact your providers as soon as possible.



## 10 WAYS TO REDUCE YOUR LYMPHEDEMA RISK

- 1 Avoid injury.** On the side where you had lymph nodes removed or had radiation treatment, do not get vaccines, injections, acupuncture, blood draws or blood pressure tests. If you had treatment on both sides, choose the side that had fewer nodes removed or was treated longest ago. In some cases, your leg may be used for these procedures. Consider wearing a **lymphedema bracelet**, also called a restricted limb bracelet, on the affected arm or arms to alert providers.
- 2 Clean cuts and scrapes quickly.** Apply an antibiotic to stop infection. If you get an infection, treat it immediately. Call your doctor if you have an infection and get a fever or feel cold, see redness or swelling, or feel heat near a scrape, cut, burn or injury.
- 3 Keep your weight down.** Extra pounds increase your risk. If you have lymphedema, losing weight may help reduce symptoms.
- 4 Use care during travel.** The lymphatic system is sensitive to decreased cabin pressure and high altitudes. If you have lymphedema, wear a compression sleeve, garment or bandages when you fly. To control swelling, use a compression glove and squeeze a rubber ball to stimulate lymph flow. Consider carrying an antibiotic with you. If you do not have lymphedema, your provider can tell you whether to wear special garments when you fly.

**5 Protect yourself from the elements.** Use SPF15 or greater sunscreen, with UVA and UVB protection. Spray bug repellent to stop bites. Use a nutrient-rich lotion to protect your skin.

**6 Dress for comfort.** Avoid tight rings, watches, bracelets, clothes, and sleeves. Try to avoid carrying heavy purses, bags or groceries on your treated side.

**7 Stay away from extreme cold and heat.** If you want to use a hot tub or sauna, the National Lymphedema Network (see page 43) suggests you limit use to no more than 15 minutes. Keep the affected area out of the hot tub.

**8 Care for your nails.** To avoid cuts that could become infected, gently push back your cuticles with a towel after showering. Do not cut them. Acrylic nails might cause infections.

**9 Exercise.** Research shows exercise may help prevent lymphedema. After surgery, begin exercise slowly and increase your effort gradually. Physical therapists and other providers can show you how to exercise to protect your lymph system. If you have lymphedema, wear bandages or a compression garment during exercise. Watch for pain and swelling.

**10 Protect your hands, fingers and arms.** Use an oven mitt for cooking and baking, and keep your affected arm away from steam. Wear gloves to garden, clean and do house repairs. An electric razor helps avoid nicks to your underarms.





# Treating Lymphedema

At one time people believed little could be done for lymphedema, but we now know that is untrue. There are several treatments to help manage and lessen the condition.

The gold standard approach is for a trained lymphedema therapist to give **complete decongestive therapy (CDT)**, which includes specialized gentle massage, wrapping with compression bandages, skin care and lymphatic exercises. The treatment takes time, sometimes daily medical office visits for several weeks.

## Basics of Complete Decongestive Therapy (CDT)

One aspect of complete decongestive therapy is **manual lymphatic drainage (MLD)**. It gently moves excess lymphatic fluid and protein from a swollen area such as the arm, breast, underarm or chest wall to a part of the body where it can drain better. This helps the fluid find new drainage pathways to replace those damaged by breast cancer treatment. Unlike traditional massage, which uses strong pressure to manipulate muscles, lymphatic massage uses a very light touch to stimulate the area just below the skin.

After lymphatic massage, the therapist may wrap the area in multiple layers of padding and “short-stretch” **compression bandages**. These woven bandages look somewhat like ACE bandages but stretch much less, which is very important for treating lymphedema. Compression bandages are wrapped with careful layering to help the

muscles pump lymph fluid. Most people wear bandages round-the-clock during the intensive treatment.

When swelling is under control, the therapist may switch you from bandages to elastic **compression garments**, such as a sleeve, hand gauntlet or chest garment. This is worn during the day and bandaging or a compression garment is worn at night. Your therapist can help you get fitted correctly.

Your therapist might also use elastic kinesio tape, which you may have seen some Olympic athletes wearing. Kinesio taping should only be done by someone trained in the technique.

Because lymphedema swells and stretches the skin, you need proper skin care to avoid injury or infection. Your therapist will monitor your skin closely and recommend ways to clean, dry and moisturize the affected area.

You will be taught decongestive lymphatic exercises to do during intensive lymphedema treatment. The movements are gentler than regular exercises and promote lymphatic flow. You must wear compression bandages or garments when exercising.

## Other Treatment Methods

**Compression pumps** with inflatable garments apply on-and-off pressure to move lymph fluid. Research recommends using pumps only if you also do complete decongestive therapy. Some pumps may worsen lymphedema by pushing fluid when the lymphatic system has not been decongested. If you are prescribed a pump, following the directions is very important.

Medicines and supplements do not reduce lymphedema. **Diuretics**, water pills that increase the

amount of urine you make, do not lessen lymphatic fluid and can cause harm.

For severe cases of lymphedema, your provider may consider a surgery called **lymph node transplant** or lymph node transfer. In this procedure, the surgeon takes lymph nodes from your groin or abdomen and transplants them to your underarm or wrist. These procedures may help lymphedema, but few surgeons perform it and results vary.

Another surgery, **lymphovenous anastomosis**, may also be considered for severe cases of lymphedema. This procedure builds new pathways in the arm by connecting the lymph vessels and the veins. Again, this procedure is only available in a few places that have surgeons who have been trained to perform it. The FDA has also cleared a laser therapy unit, for professional use, to treat the fibrosis and swelling of postmastectomy lymphedema.



## About Compression Garments

If your providers recommend you wear a compression garment for lymphedema, it's because they believe it will help reduce or prevent swelling. As you wear a compression garment during your daily activities and while exercising, it provides support and pressure that aids lymph fluid in moving around the affected area.

Research into compression garments is ongoing. Finding the right garment for you may seem daunting but your providers will be able to help. Here is more information to help you make an informed decision.

### CUSTOM AND “READY-MADE” GARMENTS

- Depending on your body and needs, you may be able to buy a pre-made garment online or in a store. Pre-made garments are for people of average proportions, and they are designed much like clothes you buy off-the-rack at department stores. These garments are available in different levels of pressure, based on the size of the body part they are worn on.
- If your limb doesn't have average proportions — for example, if your wrist is small compared to the rest of your arm — you may have a hard time finding a garment that applies the right amount of pressure to your whole body part. In this case, you may want to consider a garment specially designed to fit you.

## FABRIC KNIT

- Compression sleeves come in one of two knits: circular and flat. In circular-knit, the sleeve was continuously knit in a circle pattern so that there is no seam. Flat-knit sleeves are knitted as a sheet that was then sewn into a tube, leaving a seam.
- Flat- and circular-knit sleeves offer you the same benefit, so it is up to you to choose which you prefer. Flat-knit fabric tends to be stiffer and thicker than circular-knit, but no research has shown one knit is better than the other.

## LYMPHEDEMA-SPECIFIC GARMENTS

- In recent years, compression has become popular in athletics, especially in endurance sports. As you shop for garments, make sure you're looking for those created specifically for lymphedema. Sports garments are designed differently and, if used improperly, could cause harm. If you're unsure what kind of garment you need, talk with your healthcare team or a lymphedema specialist.



## Self-Care Is Vital

After intensive treatment reduces swelling, you must continue CDT at home. The therapist will make sure you get a garment that fits you properly. Your therapist will also teach you or a caregiver how to

- do lymphatic decongestion or massage
- wrap bandages
- wear and care for compression garments
- exercise
- take care of your skin and use risk-reduction tips

Self-care may feel like a burden, but you must do it to keep lymphedema in check.

Depending on the severity of your condition, you may not need to bandage regularly at home. You may find a small amount of swelling acceptable if you do not have to bandage daily. Some bandage or wear a compression garment only at night.

Your therapist may advise you to wear a garment all day. There are different garment types, with varying amounts of pressure. With help from your therapist, make sure yours is not tight and does not irritate your skin. A too-snug garment can make lymphedema worse. As treatment reduces swelling, you will need to change size. If you have arthritis, zippered garments can help with taking the sleeve on and off.

Self-care includes the lymphatic exercises from intensive treatment, but now you may also be able to add aerobic, resistance and stretching activities. Wear a compression garment or bandages for all exercise. Swimming is great for lymphedema. The water supports your body and helps prevent injury, while the water pressure provides a gentle decongestion. Walking and bike riding are other good choices.

Some women find yoga helpful. You also might enjoy therapeutic movement programs in a class or at home through video.

Begin exercise in small doses, at a slow pace. Pushing too hard can trigger or worsen lymphedema. Lifting weights is fine if you start with light loads and increase weight gradually. Do not overuse your arms or rush to get to a higher exercise level. If your arm begins to feel tired, stop exercising. If, during or after exercise, you notice pain or odd feelings in the arm on your treated side, you may want to exercise less intensely.

Weight loss can be part of self-care. If you are overweight and drop pounds after developing lymphedema, it can lessen the swelling. Eating a balanced, low-salt diet may help. Always talk with your healthcare team before starting any exercise or weight loss program.



## 10 BEST BITS OF BEEN-THERE ADVICE FROM WOMEN WITH LYMPHEDEMA

- 1** “See a certified lymphedema therapist before surgery or radiation to get baseline measurements and learn about precautions.”
- 2** “Realize that you are always at risk for developing lymphedema, even years after your breast cancer treatment.”
- 3** “Know the early signs of lymphedema. Many women ignore them, thinking it will go away.”
- 4** “Review how to wrap the bandages every 2 to 3 months. If you haven’t wrapped in a year, it’s hard to remember.”
- 5** “You have to be compliant. Once lymphedema develops, it’s hard to keep it under control unless you’re diligent.”
- 6** “Get every piece of information on lymphedema. Talk with someone who has it.”
- 7** “Body image-wise, my compression sleeve makes me feel a little sexy, believe it or not! I think it may be the fact that it’s black ... like Madonna from the early years. I think it also shows that I’ve been through something and I’m pretty proud I’m still here!”
- 8** “Never give up any part of your life. Learn to listen to your body. When something starts to hurt, stop what you’re doing.”



- 9** “Join whatever support group you can. You’ll get tips on things the doctors don’t tell us.”
- 10** “Treat lymphedema care as a routine you need to do. Focus on the pleasure in life, if you can, rather than the size of your arm. You can get beyond it.”





# Your Emotions and Lymphedema

Having lymphedema can stir a range of emotions. You may feel angry and betrayed that your body let you down, or feel guilty that you somehow caused your condition. You did not. If you have a changed body image or limits to your activities, you could fear that lymphedema affects your personal life or work. Since lymphedema worsens if not controlled, you might focus anxiously on what could happen next. You may feel sad or depressed.

What's more, while breast cancer may be well behind you, lymphedema presents a daily physical reminder of it that can feel distressing. If you are wearing compression bandages or a garment, people — even strangers — may ask you questions. Having lymphedema means you may have to struggle again to look and feel normal, this time with a condition that few have heard of or understand.

Some people, embarrassed by their swollen arms, hands or torsos, cover up with baggy clothes, stay inside, decline social invitations or avoid intimacy. The visible evidence of lymphedema causes some single people to worry about dating, realizing that they will have to talk about breast cancer sooner than they might have wanted to.

## Importance of Reaching Out

These emotional challenges can lower your energy for self-care, which can cause lymphedema symptoms to return or worsen. Even if you dedicate yourself, it

is hard to stick to a lifetime treatment that puts most of the burden on you. To overcome this, talk openly with your lymphedema therapist or other members of your healthcare team about what you can do within reason to manage your condition. When you make the choices, you feel more empowered and committed to treatment.

For emotional support, create a personal network of friends and family to turn to when you feel overwhelmed. Relieve your stress by talking, journaling, blogging or taking a walk. If you are struggling with your feelings or think you may be clinically depressed, connect with a provider who understands breast cancer and the impact of lymphedema. You will find counseling help at cancer centers or by getting referrals from the Association of Oncology Social Work at (847) 686-2233 or [aosw.org](http://aosw.org) or the American Psychosocial Oncology Society at (615) 432-0090 or [apos-society.org](http://apos-society.org).

Many centers and hospitals have lymphedema support groups. You can find support on our website at [LBBC.ORG](http://LBBC.ORG) or by contacting our **Breast Cancer Helpline** at [lbcc.org/helpline](http://lbcc.org/helpline) or call toll-free at **(888) 753-5222**. We can match you with a woman living with lymphedema.







# Paying for Lymphedema Care

If you have health insurance, check with your insurer to find out whether your plan covers lymphedema services and supplies. Private health plans vary. **Medicaid**, a health insurance program for people with limited income and resources, differs from state to state, so ask whether your state covers lymphedema treatment. The **Women's Health and Cancer Rights Act of 1998** requires all group insurance policies to cover the treatment of lymphedema resulting from mastectomy. About half of states have similar laws which extend to people covered by other types of policies.

Your coverage may require that you get a prescription for an evaluation and treatment by a certified lymphedema therapist. Insurers may pay for providers who are physical therapists or occupational therapists, but not massage therapists or nurses, unless they are nurse practitioners. Medicare does not cover most nurse-given lymphedema therapy, bandages, garments or compression devices, but it does cover pumps. To learn how LBBC and our partners are working to change Medicare coverage of lymphedema services, please visit [lymphedematreatmentact.org](http://lymphedematreatmentact.org).

You can file an appeal if you are denied coverage. Have your doctor submit a letter of support stating that lymphedema treatment is a medical necessity for you, along with a prescription with the lymphedema diagnosis code. Include records showing that your condition improves with therapy and paid invoices describing supplies and services.

If you are employed, you may be able to pay for lymphedema care with funds from a flexible spending or health savings account. Keep records of all lymphedema expenses because you may be able to deduct them from your federal income taxes.

## Finding Financial Help

If you find it difficult to pay for what you need, check with these groups.

**National Lymphedema Network (NLN), Marilyn Westbrook Garment Fund:** Pays for one set of garments per applicant per calendar year; must be NLN member receiving treatment at a clinic or with a therapist affiliated with NLN; must show demonstrated financial need. Call (800) 541-3259 or go to [lymphnet.org/patients/garment-fund](http://lymphnet.org/patients/garment-fund).

**Linking A.R.M.S.:** A program for medically underserved women that provides grants for lymphedema support and supplies, through a partnership between CancerCare and Susan G. Komen. Call (800) 813-4673.

Hospitals and cancer centers in your area also may have assistance programs.

### LEARN MORE

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For general information, visit [LBBC.ORG](http://LBBC.ORG) to download a copy of our *Guide to Understanding Financial Concerns*.

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# Moving Forward

If you have lymphedema, it may be hard to accept that this condition is part of your life. It is OK to acknowledge that lymphedema is unpleasant and unfair, especially after you have been through breast cancer treatment. The key is to be able to move past your reasonable and normal feelings so you can manage the therapy that will help you maintain your quality of life.

One thing that may help you is getting answers to all your questions. By connecting with others who have breast cancer-related lymphedema, finding good medical guidance and making some practical adjustments to your routine, you will be able to live with an improved quality of life despite having the condition.

Keep in mind that lymphedema therapy usually brings good results, especially if the condition is diagnosed and treated early. People talk about how they make therapy part of their daily lives, using strength gained from their breast cancer experiences, support networks, faith and even humor to put lymphedema into perspective as much as possible. Some decide to support and give advice to others dealing with lymphedema. In time, you may want to do that, too, or campaign for more public awareness and better insurance coverage for lymphedema care.

When you understand this side effect of breast cancer treatment, you can take the needed steps to enhance your health. Getting the information, evaluation and lymphedema therapy you need will put you well on track for managing the condition and enjoying your life.



# Resources

Here is a list of where to go to find out more. This list is not inclusive, and many other groups have resources that may help you.

*Information is current as of March 2019 but may change.*

## Lymphedema Organizations

**Lymph Notes:** patient education, online forums, [lymphnotes.com](http://lymphnotes.com)

**Lymphatic Education & Research Network (LE&RN):** information on clinical trials, fundraising for research and educational resources, (516) 625-9675, [lymphaticnetwork.org](http://lymphaticnetwork.org)

**Lymphology Association of North America:** list of certified therapists, (773) 756-8971, [clt-lana.org](http://clt-lana.org)

**National Lymphedema Network:** information including lists of support groups, therapists and centers, funding for garments, (800) 541-3259, [lymphnet.org](http://lymphnet.org); for assistance in filing insurance appeals, contact [nln@lymphnet.org](mailto:nln@lymphnet.org)

## Organizations That Have Information About Lymphedema

**Living Beyond Breast Cancer:** (855) 807-6386, [LBBC.ORG](http://LBBC.ORG)

**American Cancer Society:** (800) 227-2345, [cancer.org](http://cancer.org)

[Breastcancer.org](http://Breastcancer.org)

**CancerCare:** (800) 813-4673, [cancercares.org](http://cancercares.org)

**SHARE:** (866) 891-2392, [sharecancersupport.org](http://sharecancersupport.org)

**Susan G. Komen:** (877) 465-6636, [komen.org](http://komen.org)

**Young Survival Coalition:** (877) 972-1011,  
[youngsurvival.org](http://youngsurvival.org)

## Lymphedema Exercise Programs

**Healthy-Steps:** therapeutic movement program with special emphasis on exercises for lymphedema, programs in hospitals and community centers in United States, Canada and elsewhere, (844) 997-8377, [gohealthysteps.com](http://gohealthysteps.com)

**Moving For Life:** dance exercise for women affected by breast cancer, New York City; Oakland, California; and elsewhere, (212) 222-1351, [movingforlife.org](http://movingforlife.org)

## Lymphedema Supplies

Consult your healthcare provider for product recommendations. Supplies and their manufacturers include:

### Short-stretch bandages:

**Hartmann USA,** (800) 243-2294, [us.hartmann.info](http://us.hartmann.info)

**Jobst,** (800) 537-1063, [jobst-usa.com](http://jobst-usa.com)

**Lohmann & Rauscher USA,** (855) 892-4140,  
[lohmann-rauscher.us](http://lohmann-rauscher.us)

### Elastic compression garments:

**Jobst,** (800) 537-1063, [jobst-usa.com](http://jobst-usa.com)

**Juzo,** [juzousa.com](http://juzousa.com)

**LymphedIVAs,** fashion products, (866) 411-3482,  
[lymphedivas.com](http://lymphedivas.com)

**mediUSA,** (800) 633-6334, [mediusa.com](http://mediusa.com)

**Sigvaris USA,** [sigvarisusa.com](http://sigvarisusa.com)

### **Other garments:**

**JoViPak**, compression bras, vests and sleeves and foam-filled garments for lymphedema, (866) 888-5684, [jovipak.com](http://jovipak.com)

**mediUSA**, CircAid non-elastic garments, (800) 633-6334, [mediusa.com](http://mediusa.com)

### **Lymphedema alert products:**

**G-Sleeve**, alert garment, (866) 975-3383, [g-sleeve.com](http://g-sleeve.com)

### **Compression pumps with inflatable garments:**

**Bio Compression Systems, Inc.**, (800) 888-0908, [biocompression.com](http://biocompression.com)

**Flexitouch**, pump that simulates manual lymphatic drainage, (866) 435-3948, [tactilemedical.com/products/flexitouch](http://tactilemedical.com/products/flexitouch)

**Lympha Press USA**, (888) 596-7421, [lympha-press.com](http://lympha-press.com)

## Words to Know

**Axillary.** Refers to the region of the body that contains the armpit.

**Axillary lymph node dissection.** Surgery that removes many lymph nodes in the lower to mid-upper underarm.

**Bilateral mastectomy.** Removal of both breasts.

**Bioimpedance.** Technique that passes low-dose electricity through the arm to see if you have extra fluid on the side where you had cancer.

**Cellulitis.** Infection and swelling that causes skin to be warm, red and tender; may also produce fever, chills, swollen lymph nodes or blisters.

**Certified lymphedema therapist.** A trained professional who has passed a lymphedema certification course.

**Circumference measurements.** Technique that uses a tape measure to find the distance around your arm. A change in circumference of more than 2 centimeters at any place in the affected arm may suggest lymphedema.

**Complete decongestive therapy (CDT).** Treatment to manage lymphedema through special gentle massage called manual lymphatic drainage, compression bandages and garments, skin care and exercise.

**Compression bandages.** Special bandages worn after complete decongestive therapy to treat lymphedema. They are made of low-elasticity material that is wrapped around swollen areas to support and stimulate the lymphatic system, reducing swelling.

**Compression garments.** Well-fitted garments worn to reduce or prevent swelling from lymphedema. Can include vests, bras, sleeves and fingerless gloves or gauntlets.



**Compression pumps.** Devices used with inflatable garments to apply on-and-off pressure to move lymph fluid.

**CT scan.** Computed tomography scan, also called a computerized axial tomography (CAT) scan. A test that takes detailed pictures of areas inside the body, such as your arm.

**Diuretics.** Water pills that increase urine production. They do not have an effect on lymphedema and should not be used to treat it, because they can cause harm.

**Edema.** Swelling that may appear right after breast cancer surgery or radiation. This is different from lymphedema.

**Fibrosis.** Scarring. Fibrosis can prevent lymph flow.

**Lymph.** A nutrient-rich fluid that helps your body fight infection.

**Lymph node transplant.** A procedure for severe lymphedema, also called lymph node transfer, in which the surgeon takes lymph nodes from your groin or abdomen and transplants them to your underarm or wrist.

**Lymph nodes.** Small, round organs that store white blood cells and filter bacteria and waste.

**Lymph vessels.** Tiny, thin tubes that carry lymph.

**Lymphatic system.** The tissues and organs that produce, store and carry white blood cells that fight infections and other diseases. Contains a series of tiny, thin tubes called lymph vessels that carry lymph.

**Lymphedema.** A condition in which extra lymph fluid builds up, causing swelling in tissues under the skin of the hand, arm, breast or torso, on the same side that breast cancer occurs.

**Lymphedema bracelet.** Also called a restricted limb bracelet, this can be worn on the affected arm or arms to alert providers that you shouldn't have vaccines, injections, acupuncture, blood draws or blood pressure tests because of your risk of lymphedema.

**Lymphovenous anastomosis.** A procedure for severe lymphedema that builds new pathways in the arm by connecting the lymph vessels and the veins.

**Manual lymphatic drainage (MLD).** Gentle, massage-like stretching of the skin that manages lymphedema by moving lymph from the affected areas to elsewhere in the body. Sometimes called lymphatic massage.

**Medicaid.** A health insurance program for people with limited income and resources. Whether it covers lymphedema care depends on which state you live in.

**MRI.** Magnetic resonance imaging. A test that uses radio waves and a powerful magnet linked to a computer to create detailed pictures of areas inside the body, such as your arm.

**Perometer.** A computerized scanner that passes signals through your arm to measure the volume of fluid.

**Perometry.** A technique used to measure the volume and size of your arm. It passes signals through your arm to measure the volume of fluid.

**Radiation therapy.** The use of high-energy x-rays to kill cancer cells that may still be in the area where the tumor was removed.

**Sentinel lymph node biopsy.** Surgery that removes only the main lymph nodes to which the breast lymphatics drain, typically one to three nodes in your lower armpit.

**Taxanes.** Chemotherapy medicines that can prevent tumor growth by stopping cell division.

**Water displacement.** A technique used to look for lymphedema. Each arm is placed in water and the amount of water that is displaced, or spilled, is measured. If one arm causes more water to spill than the other, you may have lymphedema. Because it can be messy, this method is used less often than other methods.

**Women's Health and Cancer Rights Act of 1998.** A law that requires all group insurance policies to cover the treatment of lymphedema resulting from mastectomy.



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## CREATIVE DEVELOPMENT

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