Guide to Understanding: Lymphedema

What to expect... today, tomorrow and beyond

Steps for coping with the medical, emotional and practical concerns of breast cancer
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 spending so much time and thought choosing the best 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 call our Survivors’ Helpline at (888) 753-LBBC (5222)—whenever you need us.

Warmly,

Jean A. Sachs, MSS, MLSP
Chief Executive Officer
Looking at Lymphedema

When you hear you need breast cancer treatment, most likely your immediate concern is getting the best therapy. Your healthcare providers are focused on that same goal.

What might be overlooked is a discussion about a side effect of cancer treatment that affects some women. Lymphedema happens when lymph fluid builds up in the body, resulting in swelling and other possible symptoms.

Lymphedema can occur anytime after treatment—even many years later. In breast cancer, it usually develops under the skin of your hand, arm, breast or torso, on the same side as the cancer. As fluid builds up and the area swells, it can cause pain, reduced movement, serious infections, emotional upset and reduced quality of life.

You may have learned about lymphedema briefly during planning for breast cancer therapy but felt too overwhelmed with other concerns to focus on a possible side effect. Your healthcare team may not have told you much about lymphedema or made it sound very unlikely you would develop it. Or you may have heard nothing about lymphedema until you were diagnosed with it. What’s more, some providers know little about lymphedema.

Researchers believe that lymphedema is largely unrecognized and underdiagnosed. Studies show that between 10 and 50 percent of women treated for breast cancer develop the condition, depending on the treatment they receive. According to the American Cancer Society, the risk of upper arm lymphedema after breast cancer treatment is 15 to 20 percent.

The amount of swelling with lymphedema can be lessened with early and proper detection, skilled therapy and ongoing self-care. Even if swelling goes away, lymphedema is chronic and remains a health concern for the rest of your life. Even so, many women manage lymphedema well and move forward with their lives.

How Breast Cancer Treatment Can Lead to Lymphedema

Just under your skin, above your muscles, lies your lymphatic system, a series of tiny, thin tubes called vessels that carry a nutrient-rich fluid, lymph. The vessels travel through a web of nodes: small, round masses 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 must keep moving. When lymph nodes are hurt or removed because of surgery or radiation, scar tissue can form and keep fluid from draining. At first, the tissue affected by lymphedema may feel firm and thick. As fluid backs up, swelling and inflammation set in. If not drained, the protein-filled fluid promotes the risk for infection and more swelling.

Your risk for lymphedema depends on the breast cancer surgery you had, the location and number of lymph nodes removed and the way your body heals afterward. Surgery can cut through the lymphatic channels, breaking up the pathways where lymph travels. Surgery in the armpit (or axillary) region removes lower nodes where the breast and underarm tissue meet and may also remove higher nodes in the underarm area.

An axillary lymph node dissection removes many nodes in the lower to mid-upper underarm. A common surgery called sentinel lymph node biopsy removes only the main nodes to which the breast lymph drains, typically one to three nodes in the lower armpit. Lymphedema can develop after sentinel node biopsy, but it happens at a lower rate than with an axillary dissection.

Radiation treatment can damage your lymph system. It 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. Postmastectomy radiation, radiation to the chest wall after the breast is removed or reconstructed, can lead to lymphedema, especially if the lymph node area also is radiated. If you had both breasts removed in a bilateral mastectomy, your risk is on the side or sides where nodes were taken.

Who Gets Lymphedema?

Developing lymphedema is not your fault. We do not know why one woman gets lymphedema after breast cancer treatment while another, who has the same treatment, does not. Genes may play a role. If you have concerns about your risk, discuss them with your healthcare team. Worry about lymphedema should not keep you from getting the treatment that is best for you.

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 radiation therapy; getting an infection on the side of your body that had surgery; overuse or trauma to the hand or arm on that side; younger age at diagnosis; high blood pressure; having more than 10 nodes removed; having multiple lymph nodes with cancer; and being overweight or obese. Gaining weight after treatment may also increase your risk.

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 most 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 special gentle massage called manual lymphatic drainage, compression bandages, skin care and exercise.
5. **Compression bandages and garments.** Short-stretch (low elasticity) bandages are wrapped around swollen area to support and stimulate the lymphatic system, reducing swelling. Compression garments (sleeves, fingerless gloves or gauntlets, vests or bras) are used after CDT and must be well-fitted or they can worsen lymphedema.
6. **Lymph node.** Round mass of lymph fluid and white blood cells that filters bacteria and waste from the body.
7. **Lymph vessel.** Thin tube that transports lymph and white blood cells.
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 the affected area to elsewhere in the body for recirculation.
10. **Sentinel lymph node biopsy.** Surgery to check for cancer in the first lymph nodes in the armpit where cancer is likely to travel.

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### SECTION II

#### Know the Early Signs

If you are getting lymphedema, you could notice changes in how your skin feels or moves before anyone else sees swelling, including your provider. Be sure to speak up about any change you feel! Early diagnosis and treatment are key. Get familiar with 10 common signs of lymphedema (see page 11). Taking early action can help you get the condition under control before it gets worse.

Lymphedema often develops in stages. 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. Are the veins or tendons on one hand harder to see than they used to be? Can you see valleys between your knuckles? If you notice changes, contact your provider or get a referral to a certified lymphedema therapist (page 5).

Swelling might occur during the day and then go away at night, or start and then go away when you elevate the swollen area. When this happens, many women think there is no real problem. Follow up on these signs if they persist because they could mean you have lymphedema.

It is common to not get a medical evaluation until changes can be seen—either slowly or suddenly—and there is fibrosis or hardening of the underlying tissue. By then, the condition needs more rigorous treatment.
**SECTION II**

**Know the Early Signs**

Take note: Right after breast cancer surgery or radiation, you may have swelling, called *edema*, that is not lymphedema. If your swelling persists three to six months after surgery, get a lymphedema evaluation.

**Lymphedema Professionals**

It’s important to see a special therapist who can reduce the swelling and other problems of lymphedema, as well as teach you ongoing care. The Lymphology Association of North America (LANA) certifies therapists in complete decongestive therapy (page 6) using national standards. Therapists may also be certified by the program that trained them.

Certified providers are often physical therapists (PTs) or occupational therapists (OTs), as well as nurses, doctors or massage therapists. Physical therapists who are not certified also learn to treat lymphedema as part of their education.

When choosing lymphedema therapists, ask about their training. Several schools provide lymphedema professional education. Find out whether insurers reimburse for their services. You can find LANA-certified therapists at clt-lana.org/therapists or (773) 756-8971. Your health-care provider also may have suggestions. For lists of lymphedema treatment centers, go to lymphnotes.com/treatment.php or lymphnet.org/resourceGuide/treatmentCenters.htm. If you don’t have a computer, someone at your local public library will help you.

**SECTION III**

**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, following a few common-sense precautions and getting medical attention quickly if signs occur. It helps to see a lymphedema therapist after treatment to talk about your personal risk.

Some things seem to trigger lymphedema: trauma or stress to the arm or hand on the treated side; cuts, scrapes, burns, bites and infection; too much heat, cold or weight. If you develop an infection, it is important to see a doctor on the same day symptoms appear. Lymphedema also may occur without a known cause.

After breast cancer treatment, lymphedema can develop in the arm. Measuring the arm helps detect it. If possible, have the circumference (the distance around) of your arms measured before surgery or radiation. This gives you a baseline for the volume and size of your arm. Some facilities take baseline measurements before treatment and measure your arms regularly afterward. If size changes, you can start treatment quickly.

Other ways to measure the volume and size of your arm include water displacement (*volumeter*), electronic limb cross-sections (*perometer*) and *bioimpedance*, electrical currents that look at the makeup of tissue. For diagnosing lymphedema, some doctors use special x-rays to see lymph flow or look at the area on a CT (*computed tomography*) or MRI (*magnetic resonance imaging*) scan.

You can monitor arm size at home. Using a spring-loaded (not cloth) tape measure to keep constant pressure, measure around your arm every four to 10 centimeters. Get help if you need it. If the circumference has increased by more than two centimeters, a lymphedema therapist should check your arm.
10 WAYS TO REDUCE YOUR LYMPHEDEMA RISK

There’s little research on the best ways to lower risk, but LBBC volunteers share this advice:

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. Consider wearing a lymphedema bracelet on that arm to alert providers. 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.

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.

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. Make sure your sleeve fits you well. 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. Prevent sunburn. Use SPF15 or greater sunscreen, with UVA and UVB protection. Spray bug repellent to stop bites. A nutrient-rich lotion will nourish and protect your skin.

6. Dress for comfort. Avoid tight rings, watches, bracelets, clothes, sleeves and cuffs. Do not carry 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 suggests you limit your time 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 lead to infection, gently push back your cuticles with a towel after showering. Do not cut them. Reconsider acrylic nails because they can cause infections.

9. Exercise. Physical therapists and other providers can show you how to exercise safely and protect your lymph system. Exercise slowly and increase effort gradually, even if you were very active before treatment. If you have lymphedema, wear bandages or a compression garment during exercise. Make sure your compression garments fit you well. Watch for pain and swelling. If you stop exercise for two weeks or more, start again at a lower intensity. Lymphatic exercises (page 7) differ from general exercise and help reduce risks and flare-ups.

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. Use a thimble to sew. An electric razor will help you avoid nicks to your underarms.

Treating Lymphedema

At one time, people believed you could do little about lymphedema. We know now that is not true. There are effective treatments that help manage and lessen the condition.

The standard approach is to begin with an intensive treatment period. A trained lymphedema therapist gives complete decongestive therapy, which includes lymphatic drainage, wrapping with compression bandages, skin care and lymphatic exercises. This treatment takes time—you might have daily medical office visits for several weeks—but is the gold standard for reducing lymphedema. Talk with your provider about what treatment is appropriate for you.
**Basics of Complete Decongestive Therapy (CDT)**

Lymphatic decongestion or massage, also known as manual lymphatic drainage (MLD), gently moves excess lymphatic fluid and protein from a swollen area 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 forceful pressure to manipulate muscles and can increase swelling, lymphatic massage uses a very light touch to stimulate the region just below the skin. Lymphatic massage therapists receive special training and certification to ensure they do the technique correctly. After lymphatic massage, the therapist wraps 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 during exercise. Most people wear bandages round-the-clock during the intensive treatment period to control swelling and soften tissue.

When swelling is under control, you may switch from bandages to an elastic compression garment, such as a sleeve, hand gauntlet or chest garment, worn during the day and bandaging or a compression garment at night. Elastic and nonelastic garments are available in off-the-shelf and custom-made models. Compression sleeves cost from $50 to $300, some made from attractive fabrics. You probably will need to buy two garments so you have one to wear while the other is in the wash. Elastic garments wear out and need to be replaced every three to six months.

A certified lymphedema therapist can help you get fitted correctly for a garment. Poor-fitting garments can worsen lymphedema, so check sizing often. If swelling or your body weight lessens or increases, you will need to change size. Special garments are available if you had a bilateral mastectomy.

Some therapists also use elastic kinesio tape. You may have seen some Olympic athletes wearing it. Kinesio taping for lymphedema should only be done by someone trained in the technique.

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

Decongestive lymphatic exercises help you regain activity during the intensive treatment period. These movements differ from standard physical exercises by being more gentle and promoting good lymphatic flow. You must wear compression bandages or garments while doing the exercises.

**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, it is very important to follow the directions.

Medicines and supplements do not reduce lymphedema. Diuretics, water pills that increase urine production, do not lessen lymphatic fluid and can cause harm. Surgery, such as liposuction and removing body tissue affected by lymphedema, carries risks and does not allow you to go without compression garments.

Researchers continue to study lymphedema. A small study showed that a mechanical system, which simulates manual lymphatic drainage movements, reduced arm volume more than lymphatic massage you do yourself. Further research could find this system, which has U.S. Food and Drug Administration clearance, useful for in-home use. The FDA also cleared a laser therapy unit, for professional use, to treat the fibrosis and swelling of postmastectomy lymphedema.

**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 the 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. Others bandage or wear a compression garment only at night.

Your therapist may advise that you 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-tight 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 on a DVD.

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 two to three 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.”

SECTION V

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.
Paying for Lymphedema Care

Some women, 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 women 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, journal writing, 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 (215) 599-6093 or aosw.org or the American Psychosocial Oncology Society at (866) 276-7443 or apos-society.org.

Many centers and hospitals have lymphedema support groups. The National Lymphedema Network lists some at lymphnet.org/patients/supportGroups.htm. You can find support on our website at lbbc.org or by calling our Survivors’ Helpline at (888) 753-LBBC (5222). We can match you with a woman living with lymphedema.

Finding Financial Help

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

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 plans differ 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 women 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 (PTs) or occupational therapists (OTs), but not massage therapists or nurses, unless they are nurse practitioners (NPs). 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.

You may 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.

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...
Paying for Lymphedema Care

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 other women 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 diagnosed and treated early. Women 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 find that after connecting with other women for help, they decide to volunteer support and advice to others. 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. We hope this guide helps and supports you. Please let us know what you think.

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 January 2012 but may change.

Lymphedema Organizations

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

Lymphatic Research Foundation: information on clinical trials, fundraising for research, (516) 625-9675, lymphaticresearch.org

Lymph Notes: patient education, online forums, lymphnotes.com
Lymphology Association of North America: list of certified therapists, (773) 756-8971, clt-lana.org

Organizations that Have Information about Lymphedema

Living Beyond Breast Cancer: (888) 753-LBBC (5222), lbbc.org
American Cancer Society: (800) 227-2345, cancer.org
Breastcancer.org
CancerCare: (800) 813-4673, cancercare.org
SHARE: (866) 891-2392, sharecancersupport.org
Susan G. Komen for the Cure: (877) 465-6636, komen.org
Young Survival Coalition: (877) 972-1011, youngsurvival.org

Lymphedema Exercise Programs

Essert Associates: free guided aquatic rehab programs, CDs, links and resources on water exercise for women affected by breast cancer, maryessert.com
Healthy-Steps: therapeutic movement program with special emphasis on exercises for lymphedema, programs in hospitals and community centers in United States, Canada and elsewhere, (877) 365-6014, gohealthysteps.com
Moving for Life: dance exercise for women affected by breast cancer, New York City; Oakland, California; and elsewhere, (212) 229-8391, movingforlife.org

Lymphedema Supplies

Consult your healthcare provider for product recommendations. Manufacturers include:


Other garments: Bellisse, bras for breast or chest lymphedema, (877) 273-1683, bellisse.com; CircAid, non-elastic garments, (800) 247-2243, circaid.com; JoViPak, foam-filled garments, (866) 888-5684, jovipak.com


Compression pumps with inflatable garments: Bio Compression Systems, Inc., (800) 888-0908, biocompression.com; Flexitouch, pump that simulates manual lymphatic drainage, (866) 435-3948, tactilesystems.com; Lymph Press USA, (888) 596-7421, lymph-pa.org

10 COMMON SIGNS OF LYMPHEDEMA

Tell your healthcare provider if you notice any of these symptoms in your arm, back, chest, breast, hand, fingers, elbow or elsewhere on the side(s) where you had surgery with lymph node removal or radiation:

1. Heavy or full feeling in arm, hand, chest/breast or other area
2. Ache, soreness or pain
3. Pulling sensation
4. Swelling (may come and go)
5. Your bra feels tighter or leaves an indentation. A ring, bracelet, watch or shirt sleeve feels tighter
6. When you press the skin near the treatment site, it leaves an indented spot
7. Redness from infection or swelling
8. Skin feels warm or tight
9. Numbness or tingling (beyond what you had after surgery)
10. Decreasing flexibility at the shoulder, elbow, wrist or fingers

Living Beyond Breast Cancer’s Understanding series is designed for educational and informational purposes only, as a resource to individuals affected by breast cancer. The information provided is general in nature. For answers to specific healthcare questions or concerns, you should consult your healthcare provider, as treatment for different people varies with individual circumstances. The content is not intended in any way to substitute for professional counseling or medical advice.

More Resources

Visit lbcc.org or call (610) 645-4567 to order our other Understanding publications:

☐ Guide for the Newly Diagnosed
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☐ Intimacy and Sexuality
☐ Treatment Decisions
☐ Triple-Negative Breast Cancer
☐ Yoga and Breast Cancer
☐ Your Emotions

Guides in our Metastatic Breast Cancer Series:

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