

Breast Cancer Related Lymphedema

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Purpose

The purpose of this guide is to increase your knowledge of breast cancer related lymphedema, a common condition following breast cancer treatment, to empower you to make the best decisions about your care and treatment options. You are your best advocate. Remember, “no decision about me, without me.”

Background information

What is the lymphatic system?

The lymphatic system supports healthy fluid levels in the body by collecting excess fluid (lymph) from bodily tissues and returning it into the bloodstream. The lymphatic system also plays a vital role in the immune system, protecting the body from infection and filtering waste products. If the lymphatic system becomes disrupted, fluid cannot filter back into the bloodstream, which leads to swelling.

What is breast cancer related lymphedema (BCRL)?

When lymph nodes are removed or exposed to radiation, the lymphatic system may become disrupted. This increases the risk of developing breast cancer related lymphedema (BCRL), a condition characterized by chronic swelling in the arm or chest. BCRL is a common side effect following breast cancer treatment, impacting approximately 1 in 5 patients.

Which treatments increase my risk of developing BCRL?

Treatments including **axillary lymph node dissection** and **regional lymph node radiation** are more disruptive to the lymphatic system than **sentinel lymph node biopsy** and **chest wall radiation**. The more lymph nodes removed or exposed to radiation, the higher the incidence of BCRL. Click on the links to learn more about these treatment methods.

Why is early detection of BCRL so important?

Early detection and treatment are associated with more effective symptom management, decreased symptom severity, lower healthcare costs, and improved quality of life. Before symptoms are felt or seen, early detection and treatment can prevent BCRL from becoming chronic and irreversible. Even in later stages, once swelling is visible, early treatment can prevent irreversible skin changes and intensive treatment.

Getting your limb fluid volume measured before and quickly following breast cancer treatment from a certified lymphedema therapist (CLT) is associated with early detection and initiation of BCRL treatment. Early screening is especially important for women with greater risk factors. If something doesn't feel right, say something. Don't wait.

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Risk Factors

Patient

- Obesity
- Black race
- Lives in rural areas

Environmental

- Infection, injury, or trauma to affected arm

Treatment

- Axillary lymph node dissection
- Regional lymph node radiation
- Taxane-based chemotherapy



Signs & Symptoms

Arm Symptoms

- **Swelling**
- **Heaviness**
- **Firmness and tightness**
- **Increased arm temperature**
- **Stiffness**
- **Redness**
- **Burning sensation**
- **Numbness or tingling**
- **Pain, tenderness, or aching**
- **Feeling of a 'cord' pulling with motion**
- **Limited arm movement impacting fingers, wrist, elbow, or shoulder**

Trunk Symptoms

Trunk includes breast, shoulders, back, and sides

- **Swelling or puffiness**
- **Heaviness or fullness**
- **Tightness or firmness**
- **Dimpled hair follicles on breast**
- **Feeling of a 'ball' preventing the arm from resting at side**
- **Limited range of motion**

Early detection is essential for better health outcomes and less costly management strategies. If you report 3 or more of the above listed signs and symptoms, there is a high probability you have BCRL.

Early Indicators

Changes in ring fit and arm recurrent swelling over 3-4 weeks that continues to resolve and return are often early indicators of BCRL.

Differences in bra fit, including indentation at bands/straps or band and cup size changes are common indicators of truncal swelling.

Treatment

Complete Decongestive Therapy

CDT is the current standard of care for lymphedema management performed by CLTs. This approach combines:

- **Manual lymphatic drainage (MLD)**
 - A gentle, specialized massage that helps move lymph fluid to relieve swelling
- **Compression**
 - Bandaging or compression garment use helps manage swelling
- **Skincare**
 - Prevents dryness, irritation, and infection
- **Gentle exercise**
 - Improves arm mobility and aid in lymph drainage

Surgical Options

While there are surgical options available, it does not cure BCRL. Surgery can address complications and minimize symptoms.

Certified Lymphedema Therapists

What is a CLT and how do they help?

A certified lymphedema therapist (CLT) treats lymphatic system disorders to improve lymphatic health. CLTs are often occupational therapists or physical therapists who have received additional specialized training and credentialing.

What should I look for in a CLT?

- CLTs with a **LANA** (Lymphedema Association of North America) Certification
 - LANA requires clinicians to complete additional training and credentialing beyond a general certification program
 - LANA has a directory of LANA certified therapists
- CLTs working at **LE&RN** (Lymphedema Education and Research Network) centers or networks of excellence
 - LE&RN recognized clinics are required to meet strict standards of care and provide the latest evidence-based care
- CLTs who teach and support self-management
 - If a CLT is asking you to give up the things and activities that bring you joy, find a second opinion

How do I obtain a CLT referral?

Talk to a member of your oncology team (oncologist, radiologist) or primary care physician and request a CLT referral. Some cancer centers and hospitals have lymphedema care services available to breast cancer patients.

What Should I Do Next?

- **Ask your oncology team for a CLT referral prior to cancer treatment**
 - **Initial CLT visit should include:**
 - Education on lymphedema, risk factors, signs and symptoms
 - Education on self-monitoring recommendations, risk reduction, and infection prevention
 - Education on exercise and range of motion
 - Baseline limb volume measurements for future screening visits
- **Schedule a follow-up visit with your CLT for 3 months post-op**
 - **Follow-up visits will include:**
 - Reassessment of limb volume measurements for BCRL screening
 - Education on self-management strategies
 - Prophylactic compression garment measurements
 - Additional support and patient education

If you notice any signs and symptoms, schedule an appointment with your CLT. Do not wait. If detected early enough, BCRL can be reversed.

FAQs

What is my risk of developing BCRL?

Estimates vary, but patients who undergo axillary lymph node dissection have a lifetime risk of 15–25%. For patients who only undergo a sentinel node biopsy, without adjuvant radiation, the risk is about 6%.

When will BCRL develop after cancer treatment?

About 90% of cases develop within the first year following surgery and radiation. 95% of cases develop by the end of three years. However, it is important to remain vigilant after three years, as a small risk remains.

What steps can I take to get a CLT referral?

Ask your doctor or a member of your oncology team for a CLT referral. Your oncology team may have a CLT or lymphedema center they commonly refer patients to. If not, look for a CLT with a CLT-LANA credential or who works at a LE&RN center or network of excellence.

What can I do at home?

Gentle exercise is great for lymphatic drainage and range of motion. Good skin care will prevent sunburns, cuts, and infections that can trigger swelling. While vigilance is important, do not let your fear of lymphedema stop you from living life.

Additional Resources

[Click here for a Know Before You Go: Question Guide to Lymphedema](#)

- This guide provides questions to ask your oncology team to get a conversation started about BCRL

[LANA Certified Directory of Therapists](#)

- Search by zip code for a CLT-LANA in your area

[LE&RN Centers of Excellence](#)

- These centers follow strict standards of care

[LE&RN Resource Guide](#)

- This document contains additional FAQs and helpful patient education resources

[LE&RN Website](#)

- The LE&RN website has many resources geared towards patient education and empowerment
- You can also find additional CLT directories

[Cancer Rehab PT YouTube Channel](#)

- Kelly is a DPT and CLT-LANA who specializes in oncology and lymphedema
- Her channel is a great resource for videos on lymphatic health and exercises after breast cancer treatment

[Breast Cancer Rehab YouTube Channel](#)

- Erica is a breast cancer survivor who makes videos about breast cancer treatment side effects, exercises, scar massage, and lymphedema

What Should I Do Next?

- **Ask your primary care physician or a member of your oncology team for a CLT referral**
 - **Initial CLT visit will include:**
 - Take limb volume measurements
 - Evaluate and stage lymphedema
 - Assessment of your reported symptoms
 - Education on lymphedema, infection prevention, and exercise
 - Education on self-management for limb volume reduction:
 - Compression use
 - MLD (manual lymphatic drainage) massage
 - Measure and order compression garments
- **Depending on symptom severity, you will be scheduled for treatment 1-3 times a week until your limb volume reduces and you can manage arm/trunk swelling at home**
 - **Follow-up visits will include:**
 - Reassessment of limb volume measurements
 - Further education on self-management strategies to reduce limb volume
 - MLD massage
 - Bandaging or compression garment use
 - Order custom compression garments or a lymphedema pump if necessary

The primary goal of treatment is to help you manage your condition at home in a way that fits your lifestyle and life demands.

FAQs

Do I have to worry about swelling in my other arm or other body parts?

No. Lymphedema is a regional disease that only impacts the part of the body that was exposed to radiation or underwent lymph node removal.

Can BCRL be cured?

There is no known cure for BCRL. While surgical approaches are available, these operations reduce symptoms but do not cure lymphedema. Compression and other management strategies are still required even after surgery.

Will I need therapy for the rest of my life?

Therapy is intended to provide you with the education and tools to independently manage your condition at home. However, annual check-ins with your CLT are advised for ongoing limb volume measurements and infection prevention.

Additional Resources

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National Lymphedema Network Patient Education

- Patient education resources

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Self-Care Videos for MLD and Bandaging

- For videos on lymphedema self-management techniques