

LYMPHEDEMA

What You Need to Know



MASSACHUSETTS
GENERAL HOSPITAL



Lymphatic Education
& Research Network

Lymphedema: What You Need to Know is dedicated to Mary, a beautiful woman with lymphedema who passionately believed that everyone diagnosed with lymphedema must be provided with information about the disease and the resources to find a specialist who can determine the best treatment plan available for the patient and family.

This lymphedema education booklet is intended to give patients, families and caregivers an overview of what to consider when the diagnosis is lymphedema, recommendations for finding help and support and how to live with this chronic disease. Remember, you are not alone.

I want to extend my sincere gratitude to the Lymphatic Education & Research Network (LE&RN) for their unwavering support and guidance in the development of this booklet, and for their continued commitment to the lymphedema and lymphatic disease communities.

I also wish to extend my heartfelt thanks to Dawn Tenney, Associate Chief Nurse, Peri-Operative Services, Massachusetts General Hospital. Without her support, this important and much needed initiative would not have been possible.

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What Is Lymphedema?

Lymphedema is the abnormal buildup of lymph fluid in the tissues under the skin. Lymph fluid is a clear, straw-colored watery fluid found throughout the body. Lymph is rich in white blood cells that help to fight infection, and these white blood cells are stored in lymph nodes. The lymph fluid is circulated through our body by lymph vessels.

Damage to the lymph system can cause lymphedema. The buildup of lymph fluid can cause swelling or edema. Usually the swelling is in the arm or leg. Less often, it can develop in the breasts, trunk, head, neck or genitals.

There are two types of lymphedema. **Primary Lymphedema** is also called hereditary lymphedema. In primary lymphedema, damage to the lymph vessels is present at birth. In some cases, the swelling may be seen at the time of birth. This is called *Milroy's Disease*. The swelling from primary lymphedema can also appear later, in the early teenage years, or as an adult. **Secondary Lymphedema** is the second and most

common type of lymphedema. Surgery or cancer treatment can damage the lymph system. This puts you "at risk" for developing secondary lymphedema.

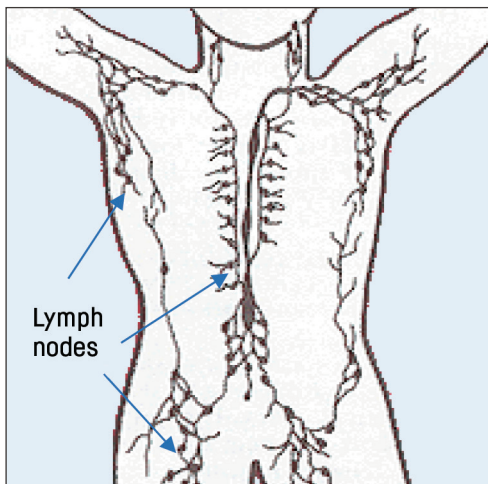
The term 'at risk' means that your medical condition has increased the chances of you developing lymphedema in the area where your lymph system was injured. This is often called the *affected area*.

Lymphedema often begins at the farthest part of the limb (hand, wrist or foot, ankle); however all parts of the affected area are at risk of developing lymphedema.

The risk for developing lymphedema increases with:

- Surgery that removes or damages lymph nodes. The more lymph nodes affected, the higher risk of developing lymphedema.

- Radiation therapy
- Being overweight
- Having active cancer
- Having an infection after surgery



RISK OF DEVELOPING LYMPHEDEMA

Location of Surgery/Cancer	Body Area at Risk for Lymphedema
Breast	Breast, underarm, arm and hand on the side of surgery or radiation
Head or neck	Face, chin and neck
Abdomen, pelvis	Abdomen, buttocks, genitals, legs and feet
Lymph nodes removed from underarm (axilla)	Chest wall, arm or hand on the side of surgery
Lymph nodes removed from groin	Leg, foot and genitals on the side of surgery

Signs of Lymphedema



Left leg lymphedema

Call your physician's office if you have any of these signs of lymphedema near the area affected by surgery or cancer.

- You have a feeling of fullness or heaviness
 - Your skin feels tight
 - Your hand, wrist, foot or ankle is less flexible
- Your clothes feel tighter in one specific area
 - Your ring, watch, bracelet or shoe feels tighter

Stages of Lymphedema



Pitting edema

There is no way to predict who will get lymphedema or when it will occur. Lymphedema can start within a few months of injury to the lymph system but it can also start much later, even decades later. Most often, lymphedema starts about 1–2

years after the lymph system is injured. Even if the swelling goes away, or if you never have signs, there is always a chance of developing lymphedema.

Stage 0

The lymph system is injured but it still works well enough to manage the flow of lymph. You can't see swelling in Stage 0. You may have early signs of numbness, tingling or fullness.

Stage I

You can see swelling as the lymph fluid begins to collect. The type of swelling is called **pitting edema**. You can test for pitting edema by pressing a finger firmly against the skin for a few seconds. A dent or pit is left behind on the skin. You may not see swelling in

the morning, but it comes back as the day goes on. Swelling typically goes away when you elevate the body part for a while.

Stage II

Swelling doesn't get better on its own without therapy. The tissues get hard and thick from scar tissue (fibrosis). You are at higher risk for skin problems, including infections (cellulitis).

Stage III

Swelling makes your arm or leg very big and you may not be able to move the limb easily. The skin may get very hard and scaly. Lymph fluid may leak from breaks in the skin (lymphorrea). You are at a higher risk for recurrent infections and other medical problems related to lymphedema.

Diagnosis of Lymphedema—What Next?

If you think you have lymphedema, contact your doctor's office right away. Your doctor may order tests to check your lymph system. You may not need any tests if it is clear the cause of swelling is lymphedema. The tests may also check for other causes of swelling like an infection (cellulitis) or blood clot (DVT).

Diagnostic tests may include:

- Doppler ultrasound
- Lymphoscintigraphy
- CT scan
- MRI scan
- Bioimpedance Spectroscopy

It is important to treat lymphedema when the signs first appear. If you are diagnosed with lymphedema, get treatment as soon as possible. It can help prevent it from getting worse.



Finding Help in Your Area



The first step in getting help to treat your lymphedema is to find a professional that works with lymphedema patients. Some professionals have special training and get certified as a **Certified Lymphedema Therapist (CLT)**. CLTs often work in a physical therapy (PT) or

occupational therapy (OT) department of a hospital or private office. Take these steps to get the best professional for your care.

- When scheduling your appointment, ask if there is a CLT on staff.
- If there is no CLT on staff, ask if a PT or OT has experience treating lymphedema patients.
- Use the internet to look for a CLT in your area.
- Check the Lymphedema Resource Guide at the end of this booklet. It has a list of sources directing you to sites on how to find a CLT.

Health Insurance—Helpful Information



There is no standard insurance coverage for the treatment of lymphedema. It is different from plan to plan. Before you start treatment, contact your insurance

company. Find out about the specifics of your plan. Lymphedema therapy is usually covered under PT and OT procedure codes.

Coverage for bandages and compression garments are considered durable medical equipment (DME). Bandages and compression garments are often used to help treat lymphedema. When calling your insurance company, talk to the DME department about your coverage for bandages or garments.

If Medicare is your insurance company, the cause of lymphedema affects coverage.

- Medicare may cover compression garments if your lymphedema is from venous insufficiency.
- Medicare typically does not cover compression garments if your lymphedema is from other causes.

Treatment



Gentle massage technique

When the swelling is mild, treatment is aimed at helping lymph flow away from the swollen area. Compression garments, exercise, and elevation are used to help lymph flow. This is usually effective in Stage 0 and Stage 1 lymphedema.

If swelling gets worse, your plan may include these four treatments. When used together, they are called **Complete Decongestive Therapy** or **CDT**. It is the plan often used by a CLT.



Multilayer bandaging

1. Manual Lymph Drainage (MLD).

A gentle massage technique that stimulates the lymph vessels to move fluid from the affected area.

2. Compression Therapy. A multilayer bandaging approach that helps move the lymph fluid out of the affected area. Once there is improvement, wearing a compression garment will help prevent further swelling.

3. Good Skin and Nail Care. This may prevent infection. A podiatrist can provide expert foot care.

4. Exercise and Movement.

Both help your circulation and move lymph fluid which improves lymphatic drainage.



Compression garment



Pneumatic compression pump

Another treatment option is **pneumatic compression pump therapy**. In this therapy, a garment is worn over the area of the body affected with lymphedema. Inside the sleeve or vest are multiple chambers, like balloons. A pump is attached to the garment. It inflates the chambers

one after the other to move lymph. Pneumatic compression therapy is often helpful during the self-care phase of lymphedema treatment. Using a pump in addition to your compression garments and other routines can help to improve swelling. It can also help with the feelings of heaviness and achiness. A CLT can guide you as you learn to use this therapy. They help decide how often to use it and for how long. Remember, *every patient is different*. Talk to your health care team to determine if a pump is appropriate for you.

Surgical Treatment Options



If lymphedema does not improve using a consistent routine of MLD, compression garments and exercise, surgery may be the next step in treatment. The right surgical procedure for lymphedema varies with each patient. It is important to find a surgeon who has had special training in lymphatic surgery.

Surgical Options:

- **Lymph Node Transfer**—lymph nodes are taken from a healthy part of your body and placed to the area affected with lymphedema.
- **Lympho-venous Bypass**—small lymph vessels are connected to small veins nearby to improve the flow of lymph fluid.
- **Liposuction**—removes the fat in the affected area that can accumulate in the later stages of lymphedema.

Living with Lymphedema

Coping

Learning that you have lymphedema can bring up a wide range of emotions and thoughts. Feelings of isolation are common. You may not know anyone else with the disease. Most people have never heard of lymphedema. You are not alone.

Two national lymphedema organizations are excellent sources of information and support:

Lymphatic Education & Research Network (LE&RN)



LE&RN is an international non-profit organization. It has several state chapters across the United States and internationally. They provide educational programs and a supportive network for patients, their families and caregivers. There is a Massachusetts chapter that you can access from their website in the Membership and Chapters link. www.lymphaticnetwork.org

National Lymphedema Network (NLN)



The NLN is a non-profit organization. It provides education and guidance to lymphedema patients and health care professionals. www.lymphnet.org

There are also many lymphedema support groups. Some people find them very helpful. Many of them

use social media to connect people with lymphedema. Check out the list of resources in the *Lymphedema Resource Guide* at the end of this booklet.

Exercise



Exercise is an important part of lymphatic health. It should be a part of your daily routine. Before starting a new exercise program, ask your health care team for guidelines. There are some types of exercise you should avoid with lymphedema, like extreme weight lifting.

Follow these tips for healthy exercise:

- Start slowly and gradually increase the amount of activities you do over time.
- Drink plenty of water, at least 8 eight-ounce cups of liquid a day.
- Wear your compression garment while you are exercising. Don't wear them while you are in the water, like when swimming.
- Swimming and water therapy are great ways to improve lymphatic health.

Keeping the Swelling Down



Lymphedema can seem to get better and worse at different times. The lymph fluid is sensitive to changes in your body and the environment. Changes are often seen with differences in:

- **Temperature**—swelling is often worse in warmer weather.
- **Food You Eat**—food with increased sodium or salt can cause more swelling.
- **Time of Day**—this depends on the location of your lymphedema. Gravity affects fluid collection in different places in your body. With arm or leg lymphedema, your swelling is usually better in the morning and worsens during the day. With head and neck lymphedema, it is often worse in the morning. Gravity helps drain the fluid from the face when you are upright.

Try these things to keep the swelling down:

- Avoid very hot compresses to the area.
- Use caution with saunas and hot tubs because heat tends to increase swelling.
- Wear sunblock SPF 30 or greater to prevent sunburns.
- Elevate your arm or leg whenever possible.

- Avoid crossing your legs while sitting if you have lower extremity lymphedema.
- Perform self-massage (manual lymph drainage), as instructed.
- Wear your compression garment. Follow washing guidelines.

Activities to Avoid



Tell healthcare workers you have lymphedema. If possible, avoid having your blood pressure and blood drawn or IVs on your arm with lymphedema. Sometimes, other health concerns are more urgent than avoiding these procedures on your affected limb.

Women with breast cancer-related lymphedema need to be careful with certain activities.

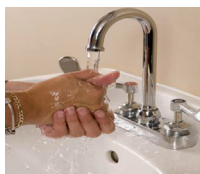
- Be careful lifting heavy objects. The amount of weight is different for each person. Start slowly and gradually increase your activity and weight if you do weight-training.
- Avoid putting anything tight around your arm, hands or fingers.

Weight Control



Maintaining a healthy weight can help decrease your risk for getting lymphedema. Being overweight makes it harder to treat lymphedema.

Avoiding Infection



The area of the body affected with lymphedema is **always** at a higher risk for getting an infection. Any break in the skin can lead to infection. A skin infection can get worse by spreading to the nearby

tissues. This serious infection is called cellulitis. The signs of cellulitis include swelling, redness and heat in the area.

Follow these steps to lower your risk for getting an infection:

- Wash any cuts with soap and water.
- Wear gloves while gardening, doing dishes, or housework.
- Protect yourself from insect bites.
- Use skin cream to avoid chapped, dry, or broken skin.
- Avoid sunburns, use sunblock with an SPF of 30 or more.

- Avoid scratches or bites from pets.
- Be careful with sharp objects or edges.
- Be very careful cutting cuticles (the skin around your nails) during a manicure or pedicure.

Contact your doctor's office immediately if the affected area becomes red, painful or swollen, or if you have fever or chills. These can be signs of infection.

Air Travel—Recommendations for Flying with Lymphedema



- Ask for guidance from a lymphedema specialist before travel.
- Wear a well-fitted compression sleeve and glove or stocking.
- You may need additional bandages on long flights.
- Avoid lifting heavy baggage without help.
- Stand, stretch and walk during flight to promote circulation.
- Drink plenty of water to stay hydrated.

Lymphedema Treatment Act

Medicare and many other health insurance plans don't cover compression treatment supplies. The *Lymphedema Treatment Act* is a federal bill under consideration in Congress. If passed, it will improve insurance coverage for the medically necessary, doctor-prescribed compression supplies that are the foundation of lymphedema treatment. You can learn more by visiting the *Lymphedema Treatment Act* website at www.lymphedematreatmentact.org

Where to Find More Information

The *Lymphedema Resource Guide* is a listing of lymphedema organizations, resources and social media support groups. Each provides additional information about care and support for patients with lymphedema, their families and caregivers. The *Lymphedema Resource Guide* is at the end of this booklet.

Contact your doctor or lymphedema therapist if you have specific questions regarding your care.

Lymphedema Resource Guide

Non-Profit Organizations

www.lymphaticnetwork.org Lymphatic Education & Research Network (LE&RN); phone: 516-625-9675

www.lymphnet.org National Lymphedema Network (NLN); phone: 646-722-7410

Additional Online Resources

www.alfp.org American Lymphedema Framework Project

www.breastcancer.org/treatment/lymphedema/treatments/pumps

www.cancer.org American Cancer Society > Treatment & Support > Managing Side Effects

www.cancer.gov/about-cancer/treatment/side-effects/lymphedema/lymphedema-pdq National Cancer Institute

www.lymphcareusa.com Online resource for patients, families, and caregivers

www.lymphaticnetwork.org/symposium-series LE&RN video library offering presentations from world-renowned doctors, lymphedema therapists and others specializing in lymphatic disease.

www.lymphaticnetwork.org/expo LE&RN's Virtual Expo is a resource for those seeking treatment options. Information on garments, pneumatic pumps and other products can be viewed directly from each company through educational videos, downloads and links.

www.lymphaticnetwork.org/living-with-lymphedema/lymphedema Lymphedema FAQs

www.youtube.com/watch?v=o_lnoL4ssFk LE&RN Symposium (*Living with Lymphedema: One Nurse's Journey as Patient and Advocate*; Catherine Holley RN, Massachusetts General Hospital, Boston, MA)

www.livestrong.org/we-can/finishingtreatment/lymphedema LIVESTRONG

www.lbcc.org Living Beyond Breast Cancer

www.lymphnotes.com/ Online resource for those living with or at risk of developing lymphedema. Also for the family, friends and therapists who care for these individuals.

www.lighthouseymphedema.org The Lighthouse Lymphedema Network is an organization of individuals who are lymphedema patients, or have an interest in lymphedema.

www.lymphedematreatmentact.org Information on the federal bill to improve insurance coverage.

Internet Blogs

www.lymphedemablog.com/ By Joe Zuther, Lymphedema Specialist (aka Lymphedema Guru)

www.lymphedemapeople.com/ A site for people with lymphedema, made by people with lymphedema

www.thelymphielife.com By Alexa Ercolano, a primary LE patient

<http://staylymphiestrong.com/> By Vern Seneriz, a primary LE patient

<http://stepup-speakout.org/> SU-SO—Together We Can Make the Difference in Lymphedema

Locate a Certified Lymphedema Therapist/Lymphedema Center

www.lymphaticnetwork.org Membership & Chapters > US State Chapter > State > Lymphedema Center. There is a growing list of states. Enter Zip Code to locate lymphedema center with CLT on staff.

www.klosetraining.com > therapist-directory

www.clt-lana.org > search > therapists

www.nortonschool.com/therapistreferrals_form.html

www.acols.com/find-therapist/

Look4LE Smart Phone App

Massachusetts Lymphedema Supportive Network

<https://lymphaticnetwork.org/chapters/massachusetts> The Massachusetts Chapter of the Lymphatic Education & Research Network (LE&RN) is a supportive network for patients, caregivers, lymphedema clinicians and others throughout Massachusetts and the surrounding region.

On Facebook: Lymphatic Education & Research Network, Massachusetts Chapter

Social Media Support Groups/Networks

Official Lymphie Strong Inspiration Group (Facebook)

The Lymphedema Running & Fitness Club (Facebook)

Lymphedema (Facebook)

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