

Lymphedema: Everything You Need to Know



**PATIENT
EDUCATION**

What is Lymphedema?

Lymphedema is an abnormal buildup of protein-rich fluid (lymph) that causes chronic inflammation and reactive fibrosis of affected tissues. It can interfere with wound healing and cause significant damage to the skin.

Symptoms of lymphedema include swelling of a body part or parts, skin changes, discomfort, restricted range of motion, and pitting or non-pitting edema.

Lymphedema can occur anywhere in the body, but is usually seen in the arms or legs. If left untreated, lymphedema can cause:



- ✓ a progressive hardening of the affected area
- ✓ increased size of an extremity
- ✓ hardening of dermal (skin) tissues
- ✓ hyperkeratosis
- ✓ papillomas

Lymphedema...

- ...affects over 2.5 million Americans, lymphedema remains poorly understood in the medical community. For many people, lymphedema lessens their quality of life.

- ...is diagnosed by medical history, physical exam, and comparing the measurements of the affected and non-affected limbs.
- ...can develop when lymphatic vessels are missing or not working as they should (primary); or when lymph vessels are damaged or lymph nodes have been surgically removed (secondary).
- ...is a chronic condition, which means that it can be a lifelong challenge. It can be managed, but it is neither curable nor life-threatening.
- ...should not be confused with edema caused by venous insufficiency/poor circulation. However, if not treated, it can progress into a combined venous/lymphatic disorder. This disorder is treated in the same way as lymphedema.

Who's at Risk?

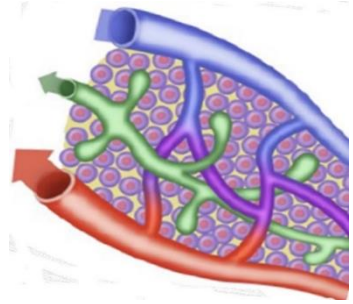
You may be at higher risk of developing lymphedema if you:

- have gynecological, melanoma, prostate, head/neck, or kidney cancer treated with lymph node dissection (removal) and/or radiation therapy
- have a history of cellulitis
- have certain pre-op and postop factors such as a high body mass index (obesity), tumor location, delayed wound healing, postop infection, and postop hematoma or seroma

While those at higher risk can take risk-reduction measures in their daily lives, even the most watchful person has no guarantee that they won't develop lymphedema.

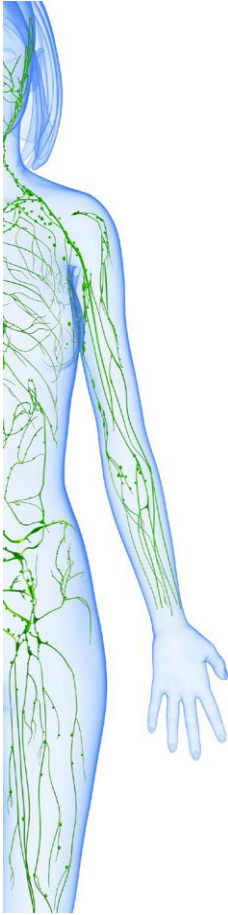
The Normal Lymphatic System

- The lymphatic system includes lymph vessels, nodes, ducts, , and organs that work together to drain/collect lymph from your tissues and return it to the bloodstream. The lymphatic system is also an important part of the immune system. It produces *lymphocytes*, white blood cells that fight bacteria and viruses.
- Lymph vessels are microscopic channels that contain a colorless fluid called lymph.
- Lymph is made of white blood cells (lymphocytes that attack bacteria and viruses), chyle (fluid from intestines that contains proteins and fats), and waste products from tissues and cells. Lymph passes through nodes, or valves, located every 1-2 centimeters (cm) in the lymph channels. As the lymph passes through the nodes, they remove harmful bacteria and viruses.



The 2 areas with the most lymph nodes are the head/neck (approximately 170 – 200 nodes) and deep in the abdomen (approximately 400 – 700). Smaller groups of nodes are located in the armpits (axilla) and groin (inguinal folds). Not all people are born with the exact same number of lymph nodes. It is believed that most individuals have 500 – 1500 nodes, some as small as a sesame seed and others as large as an olive.

What Causes Lymphedema?



Primary Lymphedema: Lymphedema can occur from idiopathic (unknown) causes. This is called primary lymphedema and has been known to affect from one to as many as four limbs and/or parts of the body. Primary lymphedema can be present at birth, or associated with arterial-venous abnormalities (AV malformations) such as hemangioma, port-wine stain, Klippel Trenaury syndrome (KTS), and Parker-Weber syndrome (PWS).

The most common form of primary lymphedema is *lymphedema praecox* which typically appears during puberty, primarily in girls, and usually affects one lower extremity. A second form of primary lymphedema is *lymphedema tarda*, which can occur in both male and female adults, typically between ages 25 – 35.

Secondary Lymphedema: Secondary lymphedema, or acquired lymphedema, can develop as a result of surgery, radiation, infection, or trauma. The number one cause of lymphedema in the US is treatment for cancer. This includes certain surgeries, radiation, and some chemotherapy. Other non cancer-related surgeries (as well as trauma and infections) that disrupt lymphatic pathways, can cause lymphatic impairment and eventually lead to the onset of lymphedema.

Lymphedema can develop immediately after surgery, or weeks, months, or even years later. It also can develop when chemotherapy is unwisely given in an area already affected (the side on which surgery was performed) or after repeated aspirations of a seroma (drawing fluid out of a fluid pocket that commonly occurs after surgery) in the axilla, breast, or groin. This often causes localized infection, which leads to lymphedema. For some patients, taking tamoxifen, a medication used for breast cancer prevention, also contributes to developing lymphedema.

Radiation therapy used in the treatment of various cancers can damage otherwise healthy lymph nodes and vessels. This causes scar tissue to form, which interrupts the normal flow of lymphatic fluid. Radiation can also cause skin dermatitis or burn similar to sunburn.

What are the Symptoms of Lymphedema?

Lymphedema can develop in any part of the body. Signs or symptoms include:

- sensation of fullness or heaviness in a limb(s)
- tightness of skin, decreased flexibility in a joint
- difficulty fitting into clothing in one specific area
- tight feeling in ring, watch, or bracelet

If you notice persistent swelling, it is important to seek immediate medical advice. Early diagnosis and management generally improve the outcome.

Lymphedema Develops in Stages, From Mild to Severe

Stage 0: The lymphatic system is becoming damaged but swelling may not be evident. Most patients have no symptoms but some report a feeling of heaviness in the limb. Stage 0 may exist for months or years before lymphedema becomes visible.

Stage I: (spontaneously reversible): Lymph has collected and caused swelling. Swelling will go down if limb is elevated. There is a “pitting” or indentation when you press the skin with your fingertips. A limb may feel “fine in the AM” but feel heavy or have swelling by the end of the day.

Stage II: (spontaneously irreversible): Pitting becomes progressively more difficult due to a buildup of connective/fibrotic tissue. At this stage, the edema does not lessen when you elevate the limb/area.

Stage III (lymphostatic elephantiasis):

- Greater accumulation of lymph makes pitting no longer possible
- Thickening, hardening, or scarring of the tissues (fibrosis and sclerosis)
- Skin changes such as warty overgrowths
- Skin becomes susceptible to deep, poorly healing wounds and is in danger of infection
- Fat deposits occur or skin has a cornmeal appearance (hyperkeratosis)
- Skin may thicken or discolor
- Lymph (fluid) may leak or weep through damaged skin

How is Lymphedema Treated?

The recommended treatment plan is based on the Complete Decongestive Therapy (CDT) method which consists of:

- A. Manual Lymph Drainage (MLD)
- B. Compression Bandaging
- C. Remedial/Lymphedema Specific Exercises
- D. Meticulous Skin and Nail Care
- E. Instructions in Self-Care

- **Manual Lymphatic Drainage (MLD)** is performed by an occupational or physical therapist who is certified in the treatment of lymphedema. It is a gentle manual treatment that improves the activity of the lymph/blood circulatory system. In lymphedema, MLD reroutes the lymph flow around blocked areas into more centrally located healthy lymph vessels, which drain into major veins.
- **Compression Bandaging** is used in conjunction with manual lymphatic drainage. Short stretch bandages are applied to increase tissue pressure, improve the efficiency of the muscle and joint pumps, and prevents the lymph fluid that has already been drained from re-accumulating.
- **Remedial Exercises** are performed with the bandages or support garments in place. These exercises are specifically designed to increase lymph vessel activity. Increased activity then increases the volume of lymph that is moved out of the affected limb. These exercises also improve lymph circulation.

Goals of CDT treatment

- ✓ Use the remaining lymph vessels and other lymphatic pathways
- ✓ Decongest swollen limbs
- ✓ Eliminate fibrotic (scar) tissue
- ✓ Avoid the re-accumulation of lymph fluid
- ✓ Prevent/eliminate infections
- ✓ Maintain normal or near normal size of limb



Frequently Asked Questions

Will my Lymphedema Ever Go Away?

It is extremely rare for lymphedema to spontaneously resolve. It is not considered a curable condition. Rather, it is a condition that requires life-long management including meticulous skin care, compression bandaging, use of compression garments, and lymphedema specific exercise.

Why Don't Water Pills Help my Lymphedema?

Lymphatic fluid is made up of proteins, salts, white blood cells, and water and it carries debris from tissues and cells to the lymph nodes for filtration. Diuretics do not help manage lymphedema.

Will my Insurance Cover Treatment for Lymphedema?

Most insurances will cover skilled therapy sessions for the treatment of lymphedema. Not all insurances cover compression bandages and/or garments needed for treatment. This can best be addressed on a one-to-one basis with your therapist.

Does Lymphedema Cause Pain?

Swelling can stretch tissues, put pressure on nerves or cause scar tissue to form and limit range of motion. The most effective way of reducing pain or discomfort is by treating lymphedema and reducing swelling.

Can I Have Surgery to Cure my Lymphedema?

There are a few types of micro-surgical procedures that are being trialed on a limited number of patients. Unfortunately, success has been limited in most cases and, in some cases, have made the lymphedema worse. Additional research is needed.

