Lymphedema Information

Lymphedema is a swelling of a body part, most often an extremity, caused by the abnormal accumulation of lymph fluid. It can occur in the face, neck, pelvis, genitals, abdomen, and lung. Although it is a chronic and progressive condition, it can usually be brought under control by good care of the extremity and attention to certain basic rules. Lymphedema is compatible with a normal and active lifestyle.

This condition most often causes a feeling of heaviness, tightness, or discomfort, and can lead to repeated episodes of infection (cellulitis and lymphangitis). Sometimes thickening of the skin, hardening of the limb, and leakage of lymph fluid may occur. Although many physicians think of lymphedema as a rare condition, it is in fact fairly common, affecting roughly one percent of the population in the USA.

There are two types of lymphedema:

1. **Primary Lymphedema** occurs without any obvious cause. It may be present at birth (lymphedema congenita), occur in the teen years (lymphedema praecox), or develop after age 35 (lymphedema tarda). Some cases are familial as well as congenital. Primary lymphedema is more common in females and occurs more often in the lower extremities.

2. **Secondary lymphedema** is caused by injury, scarring or excision of the lymphatic vessels. In this country, this usually occurs as a result of previous radiation and/or surgery of the lymphatics. Such treatments are commonly given for cancers of the breast, uterus, bladder, ovary, prostate, or testicle and for malignant melanomas and lymphomas. Occasionally, secondary lymphedemas are caused by trauma to, or chronic infections of, the lymphatic system.

It is estimated that there are over two million cases of secondary lymphedema in the United States, most the result of breast cancer therapy. In third world countries, secondary lymphedema is much more common, owing to the prevalence of parasites which obstruct the lymphatics.

<table>
<thead>
<tr>
<th>Factors that contribute to lymphedema</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Surgery</td>
</tr>
<tr>
<td>• Combined surgery and post-operative infection</td>
</tr>
<tr>
<td>• Infections</td>
</tr>
<tr>
<td>• Constricting clothing or jewelry</td>
</tr>
<tr>
<td>• Heavy breast prosthesis</td>
</tr>
<tr>
<td>• Obesity</td>
</tr>
<tr>
<td>• Combined surgery and radiation therapy</td>
</tr>
<tr>
<td>• Sedentary lifestyle</td>
</tr>
<tr>
<td>• Dependent limb position</td>
</tr>
<tr>
<td>• Trauma to remaining lymphatics</td>
</tr>
<tr>
<td>Impact on client</td>
</tr>
<tr>
<td>----------------------------------</td>
</tr>
<tr>
<td>• Swollen limb or body part</td>
</tr>
<tr>
<td>• Heaviness and limitation of motions</td>
</tr>
<tr>
<td>• Skin thickening, lymph leakage through skin</td>
</tr>
<tr>
<td>• Multiple hospitalizations</td>
</tr>
<tr>
<td>• Constant medical care and expense</td>
</tr>
</tbody>
</table>

The National Lymphedema Network (NLN) has developed guidelines on several issues pertinent to persons with lymphedema or at-risk for lymphedema. To see the full content of position statements on Risk Reduction, Exercise, and Air Travel, visit the NLN website at www.lymphnet.org. Following are highlights from these position papers:

**Risk Reduction Practices**

- Protect the skin of the affected extremity against trauma/injury to reduce infection risk. This includes avoiding needle sticks, blood draws, blood pressure cuffs, sunburns, insect bites, etc. Watch for signs of infections such as rash, redness, increased heat, fever or flu-like symptoms and report these to your physician immediately. Cellulitis is a common infection.

- Carefully and gradually increase activity level with the affected extremity (see “Exercise” summary below for more information).

- Avoid constriction to limb. This includes tight jewelry or clothing, blood pressure cuff.

- Wear appropriate, well-fitting compression garments, especially during strenuous activity or during air travel.

- Avoid extremes of temperature, including hot tubs and saunas.

- For lower extremities, avoid prolonged sitting or standing.

**Rationale:**

The lymphatic system helps fight infections. Persons with a reduced lymphatic system are at risk for developing infections in the affected region (i.e., upper back, chest, and arm if lymph nodes have been removed from the armpit). A small puncture or scrape can allow bacteria to enter the skin. Normal bacteria living on the skin can sometimes grow and cause an infection, even without any apparent opening in the skin. These infections can quickly spread via the bloodstream and cause serious complications.

**Exercise**

NLN’s stance on exercise precautions has changed significantly in the past few years, partly due to new research. NLN provides general recommendations for designing an exercise program as well as the rationale for exercise as part of a lymphedema treatment program and home program. Their position can be summarized as follows:
Exercise programs should include flexibility/stretching, resistive, and aerobic activities. These may include working with weights, yoga, swimming, etc.

Persons “at risk” for developing lymphedema, who do not have clinical symptoms, as well as those with a confirmed diagnosis, need to be cautious when beginning an exercise program. For those with a confirmed diagnosis of lymphedema, wearing a compression sleeve during exercise is recommended.

If symptoms do appear, the person should contact their physician and/or a qualified lymphedema therapist. Exercise may be modified.

Compression levels of 20-30 mm/Hg for an upper extremity or 30-40 mm/Hg for lower extremity are advised for prevention or for existing mild lymphedema. Higher compression levels may be needed depending on the individual case.

Exercising in water (cool to moderate temperature) provides some compression, and garments can be removed during this time.

Rationale:

Exercise is integral to a healthy lifestyle, and lymphedema exercises are important to assist with lymph drainage (muscle contractions and deep breathing help lymph flow).

However, exercise increases blood flow, increasing the lymphatic load; and also increased muscle metabolism and metabolic waste. An impaired lymphatic system may become overloaded during strenuous exercise. Improper exercise can cause trauma and inflammation. Exercises may need to be modified to maximize positive effects and minimize negative effects on the lymphatic system.

Air Travel

Anecdotal evidence suggests that air travel can precipitate swelling in persons at risk for lymphedema, and increase swelling for those already diagnosed. Therefore, the NLN has developed a position paper that includes factors which may explain this phenomenon. Their recommendations can be summarized as:

- Wear a well-fitted compression garment during air travel (at risk individuals as well as those diagnosed).
- If using compression bandages, use these instead of, or in addition to, a compression garment.
- Try to get an aisle seat to allow more leg room (lower extremity lymphedema).
- Get a note from your physician or therapist to explain the need for garments or bandages (security personnel may ask for this).
- Try not to lift or carry baggage more than absolutely necessary.
- Move around when possible on the plane.
- Increase water intake.
- Wear a lymphedema alert bracelet or necklace.

Rationale:

Cabin pressure during flight is less than atmospheric pressure, and may cause alterations in interstitial pressures - changes in ultrafiltration and resorption. Fluid remains in the
extracellular spaces and may trigger lymphedema or make it worse. Also, sitting for long periods of time can cause edema – we need the active muscle movements to help “pump” both blood and lymph fluid into the respective vessels. Carrying heavy luggage can put too much of a burden on an impaired lymph system. And, finally, dehydration causes our bodies to “hold onto” water, and can make tissues swell.

The use of compression, such as a compression armsleeve or compression bandages, will provide external pressure on the extremity and decrease the potential for fluid accumulation.

See the website, www.lymphnet.org, for more detailed information.

**Lymphedema treatment basics for clients**

Currently, the best treatment for lymphedema is Complete Decongestive Therapy (CDT). Treatment is divided into 2 phases, acute or intensive therapy, followed by maintenance:

**Phase 1: Acute/Intensive Therapy**

The purpose of the acute phase of therapy is to decongest or remove as much fluid as possible from the swollen limb. It is also helpful in treating hardened or fibrotic tissue so that the tissue is softer and healthier, enabling lymph fluid to travel more readily through the vessels to be returned to the circulation. Acute therapy:

- Requires 3-5 visits per week, usually for 3 weeks or more.
- Each session takes about an hour.
- Includes Manual Lymph Drainage (MLD) – a specialized manipulation of the skin that feels like a light massage; this enhances the lymphatic system’s natural ability to drain fluid from the tissues.
- Includes compression wrapping with short-stretch bandages over padding. These bandages stay on day and night and are removed only for bathing. They are NOT Ace wraps, which are much too elastic for this treatment.
- Exercise to help the lymphatic system work more efficiently.
- Patient and family education and training.

**Phase 2: Maintenance Therapy**

Patients must continue to take measures after the acute phase to manage their lymphedema so that it does not get worse over time. Maintenance includes:

- Self-massage using the MLD techniques learned in therapy.
- Wearing compression garments on the affected limb. There are garments designed for daytime wear and for nighttime wear, when vascular pressures are lower. Not everyone needs a nighttime garment.
- Continued use of short-stretch bandages at times. Some people use these a few days a week, a few days a month, or only when the edema seems worse than usual.
- Following the skin care precautions and other risk-reduction practices learned in therapy.
- Replacing compression garments as recommended, usually every 6 months with normal wear and care.
- Returning for periodic assessment and repeated therapy, if indicated.
Lymphedema is a chronic but manageable condition, and most people are able to continue all their normal activities. Lymphedema alone is not a life-threatening condition, although some people with lymphedema are susceptible to serious infections that require immediate treatment. For more information, go to www.lymphnet.org, or talk to your healthcare provider.

**Frequently asked questions and answers about lymphedema**

1. **After surgery, how long before lymphedema develops?**

   Lymphedema is unpredictable in its onset. It can occur immediately after surgery or radiation for breast cancer, it may occur years later, or not at all. Some experts believe there is a “latent stage” of lymphedema, during which swelling is not visible but the at-risk limb is slowly developing the problem.

2. **Why do some people develop lymphedema while others do not?**

   One explanation may have to do with anatomical differences among individuals. Some people have more lymphatic vessels to start with, and can compensate for the damage caused by surgery/radiation. A person who has only one node removed may develop lymphedema, while another person who has many nodes removed may not develop it at all. At this time, there is no proven method to predict who will get lymphedema. We do know some of the risk factors include surgery, radiation, infection, obesity, and sedentary lifestyle.

3. **Why can’t the excess fluid be drained with a needle?**

   The excess fluid is part of the blood circulation. It is distributed throughout the tissue, in the intra cellular spaces under the skin and surrounding the muscles and bones. It is not localized to one spot, as in a cyst or seroma, and cannot be drained with a needle. In addition, every time the heart beats, it is pushing more fluid (blood) out to the tissue. There is a continuous system for getting fluid out to the tissue (via the arteries with the heart’s pumping action) and returning fluid from the tissue to the heart (via the blood veins and lymph vessels).

4. **Does this extra fluid in one arm (or leg) affect my overall health?**

   It can. A swollen arm can be susceptible to infections such as cellulitis. Cellulitis can develop in an arm with lymphedema because the lymph nodes that usually filter out bacteria and waste products are damaged or missing, and the overall immune protection in that arm is now compromised. Cellulitis can start in the arm, and then travel through the bloodstream to all parts of the body. This is called septicemia, and it is a serious and sometimes life-threatening condition. Not everyone with lymphedema will get cellulitis, but it is important to know the symptoms: skin redness and/or heat, dimpling texture of the skin similar to an orange peel texture, fever, malaise, aching joints, or increased swelling in the limb. Antibiotics are effective in treating cellulitis and should be started as soon as symptoms appear.

5. **Once you have lymphedema, does it ever go away?**

   Lymphedema is a permanent condition. It is different from the temporary swelling (edema) you see right after surgery or right after an injury. Lymphedema may fluctuate over time. Some people have what seems to be an acute flare-up, then the swelling goes down and stays down indefinitely. However, for most people, lymphedema slowly worsens over time, with periods of increased swelling followed by partial reduction, or progressive swelling over time.
6. What effect does long-term lymphedema have on my arm?

If not treated, long-term lymphedema causes permanent tissue changes that cannot be reversed. These include a loss of skin elasticity and hardening of soft tissue called “fibrosis”, which further diminishes the ability of the body to move blood and waste products through the tissue. Some people develop warty growths, shiny taut skin, diminished hair growth in the affected area, weeping blisters, and recurrent infections. These complications of lymphedema usually develop slowly over a period of years, and much can be done to minimize them with a good home maintenance program and/or periodic therapy.

7. What’s the difference between using compression bandages versus compression garments to control the swelling?

Bandages are effective for reducing edema. They are used during the treatment phase to try to get rid of as much swelling as possible, and can be used indefinitely after that. Compression sleeves are used as a maintenance tool to help prevent the swelling from increasing after reduction has taken place. While bandages can be worn 24 hours a day, sleeves should only be worn during the daytime. If compression is needed at night, we recommend that you bandage your arm at night or purchase a garment made especially for night wear.

8. Once my swelling is brought down, can I be certain it’s gone for good?

No. The treatment for lymphedema is not a cure but a management technique to help control swelling. The affected arm is always going to be at risk for swelling. Some people are fortunate and are able to wear a compression sleeve only part of the time, for instance while they’re doing heavy housework. But others have to keep some kind of compression on their arm day and night. Nutrition, medications, activity, weight gain, illness and many other factors can affect lymphedema. It is important to monitor your arm and adjust your maintenance program accordingly. Some people return for treatment periodically as their arm changes over time.

9. Does strenuous exercise (or heavy work) make the swelling worse?

When you are working the muscles in the affected area strenuously, the muscles need more oxygen (carried by the blood). Your heart pumps more blood to these muscles. More blood means more fluid to be filtered and returned to the heart via the blood vessels and the lymph vessels. If the lymphatic system is compromised and cannot keep up with this extra fluid load, increased swelling may result. Moderate activity is preferred, as the active muscle contractions actually help push the fluid back into the vessels without creating a greater demand for blood to the area.

10. I am not willing to give up my regular activities. If I wear a sleeve can I do everything I’m used to doing?

Wearing a sleeve does offer some protection. However, lymphedema can still get worse even while using a compression sleeve on the arm. You have to decide what level of risk you’re willing to take. You may be willing to accept some edema in exchange for doing something you love (i.e golfing, gardening, or aerobics). You just need to make an informed decision, take as many precautions as you reasonably can, monitor how your arm reacts to the activity, and adapt accordingly. Even if the swelling seems to go back down after you stop the activity, the effects are cumulative. Each episode of swelling further taxes the lymph system, stretches the soft tissue, and makes future edema problems more likely.
11. Are there any medicines I can take or surgical interventions to cure lymphedema?

Not at this time. Microsurgical techniques including lymphovenous anastomoses (connecting lymph vessels to blood vessels) have not proven successful. A newer procedure called lymph node transfer may be done as part of reconstructive surgery; it is available in only a few locations. There are currently no FDA-approved medications for the treatment of lymphedema. Diuretics have a limited effect and are not recommended for treating lymphedema. Diuretics are more effective at removing water molecules from the tissue than protein molecules. With lymphedema, there is a high concentration of protein molecules. Protein attracts water. Removing water and leaving protein behind creates a vicious cycle whereby protein is more concentrated in the tissue, attracts more water, etc. Complete decongestive therapy, compression garments, and a lifelong maintenance program are the best tools for managing lymphedema at this time.

12. How do other people cope?

There are local and national resources for information and support. Julie Peterson is the facilitator of the local Mid-Missouri Lymphedema Awareness Network. Call Julie (573) 814-2968 for more information. The National Lymphedema Network has an excellent website, www.lymphnet.org or you may contact them at (510) 208-3200.

Content used with permission from the National Lymphedema Network (NLN)