

Lymphedema Guidelines

Twenty-Four Ways to Protect Yourself

Adapted from the American Lymphedema Institute and Mayo Clinic

These guidelines are provided for informational and educational purposes only. Please discuss all treatments with your doctor

Your lymphatic system is crucial to keeping your body healthy. It circulates protein-rich lymph fluid throughout your body, collecting bacteria, viruses and waste products. Your lymphatic system carries this fluid and harmful substances through your lymph vessels, which lead to lymph nodes. The wastes are then filtered out by lymphocytes — infection-fighting cells that live in your lymph nodes — and ultimately flushed from your body.

Lymphedema occurs when your lymph vessels are unable to adequately drain lymph fluid, usually from an arm or leg. Lymphedema can be either primary or secondary. This means it can occur on its own (primary lymphedema), or it can be caused by another disease or condition (secondary lymphedema). Secondary lymphedema is far more common than primary lymphedema.

Causes of Secondary Lymphedema: Any condition or procedure that damages your lymph nodes or lymph vessels can cause lymphedema.

Surgery. Removal of or injury to lymph nodes and lymph vessels may result in lymphedema. For example, lymph nodes may be removed to check for spread of breast cancer, and lymph nodes may be injured in surgery that involves blood vessels in your limbs.

Radiation treatment for cancer. Radiation can cause scarring and inflammation of your lymph nodes or lymph vessels.

Cancer. If cancer cells block lymphatic vessels, lymphedema may result. For instance, a tumor growing near a lymph node or lymph vessel could enlarge enough to block the flow of the lymph fluid.

Infection. An infection of the lymph nodes or parasites can restrict the flow of lymph fluid. Infection-related lymphedema is most common in tropical and subtropical regions and is more likely to occur in developing countries.

Causes of Primary Lymphedema: Primary lymphedema is a rare, inherited condition caused by problems with the development of lymph vessels in your body. Specific causes of primary lymphedema include:

Milroy's disease (congenital lymphedema). This disorder begins in infancy and causes lymph nodes to form abnormally.

Meige's disease (lymphedema praecox). This disorder often causes lymphedema around puberty or during pregnancy, though it can occur later, until age 35.

Late-onset lymphedema (lymphedema tarda). This occurs rarely and usually begins after age 35.


The American Lymphedema Institute has compiled the following guidelines to empower you to protect yourself. By following them, you may be able to protect yourself from developing lymphedema, or perhaps postpone its onset. If you have lymphedema, adhering to these guidelines may help prevent further deterioration.

If you notice any swelling, seek medical advice to determine the cause of the edema. Swelling may occur for a number of medical reasons and these should be ruled out before proceeding with lymphedema treatment.

1. Keep the entire at-risk quadrant spotlessly clean. Natural gentle cleansing products are strongly encouraged. Dry skin in a gentle but thorough non-vigorous fashion. Pay special attention to creases in the skin and the areas between toes and fingers.
2. Make certain all fabric making contact with the skin is regularly laundered. This includes bandages and compression garments.
3. Use a top quality moisturizing lotion to help maintain the integrity of the skin. The lotion you choose should not contain alcohol, dyes, petroleum products, talc or perfumes. (Note that pure essential oils have a fragrance, but are not considered perfumes.) The lotion should also have antiseptic properties and correct ph. If you have lymphedema, apply a lotion recommended by your physician or therapist before and after removing bandages or compression garments, and after bathing.
4. Avoid chemical hair removers. If possible, use a well-maintained electric razor, replacing the heads regularly. Because of the danger of cuts and nicks, we do not recommend using a regular razor. If you do use one, wash the blades in hot soapy water, and change them often.
5. Avoid extreme temperature changes when;
 - a. Bathing, showering, swimming.
 - b. Washing anything; dishes, floors, laundry, etc.
 - c. Receiving therapeutic treatments.
 - d. At the gym or home; no sauna or hot tub.
6. Protect the affected quadrant from weather extremes;
 - a. In hot weather seek air conditioning and keep the limb cool.
 - b. In cold weather seek central heating. If you must go out, have the at risk quadrant well bundled, but not sweaty.
 - c. In sunny weather, protect the limb with sunscreen and/or covering.
7. Medical care, such as injections, blood pressure, drawing blood, allergy test, etc., needs to be performed on an unaffected limb. (Note: A leg can often be used if both arms are at-risk.) Any procedure, which punctures the skin in the affected quadrant, is to be avoided, including acupuncture. Medic Alert tags can be purchased to alert health care givers to your condition.
8. Avoid all tight clothing, jewelry, and elastic bands on the affected limb, including watches, rings, and stockings.
9. Be careful cutting nails. Do not nick skin or cut cuticles. If someone does your nails for you, inform them of your risk. If you must push back cuticles, use a cuticle stick covered with cotton.
10. Avoid all types of trauma; cuts, scraps, bruises, burns, including sun burns, sports injuries, insect bites, all animal bites and scratches, and forceful impact. This does not mean withdrawing from living, but be sensible and protect yourself; use seatbelts, use a thimble if you sew, wear rubber gloves when washing dishes or gardening, wear closed shoes to avoid foot injury for an at-risk leg. Wear insect repellent when outdoors, sunscreen and clothing to cover an at-risk quadrant. Any measure you can take to prevent the onset of lymphedema is worth the effort, as it can mean avoiding a lifetime of maintenance therapy.
11. Avoid vigorous pushing, pulling, or lifting with the affected limb. Do not kick or slide heavy packages with an affected leg. Do not use over the shoulder straps on an affected arm. Do not lift anything over 15 pounds, less if you are out of shape or the weather is hot and humid. This includes the lifting of babies, children and



pets. Carry packages, purses, or briefcases only on your unaffected side, and ask baggers at the store to place your bags in your car for you.

12. Exercise is important. However, if the affected limb begins to ache or feels tired, rest it immediately, and elevate it if possible. Consult a lymphedema specialist before proceeding with an exercise routine. Safe recommendations are walking, swimming or water exercise. If you have lymphedema, it is important to be compressed during exercise (unless you are in a pool).
13. Avoid any repetitive movements, especially those against resistance.
14. Never do anything to exhaustion. Your at-risk quadrant will fatigue more quickly than the rest of your body, and will take longer to recover from physical exertion. If your arm or leg begins to ache, rest and elevate the limb. If elevation does not alleviate the symptoms, see your physician.
15. Barometric pressure is reduced at high altitudes, and can lead to the onset of lymphedema, or exacerbate the condition. Therefore, a compression garment is extremely important if you travel by air or hike in high altitudes. This is recommended even if you don't have lymphedema. It becomes essential if you have lymphedema, even if the swelling has subsided. In this case, you should consider wearing bandages when flying, as they offer greater protection than a compression garment. For an at-risk limb, over the counter garments are available for a modest cost. This small step may prevent a lifetime of maintenance.
16. If you have had an axillary (armpit) dissection you may want to wear soft pads under your bra straps, as this protects the lymph nodes and vessels around the collarbone. Avoid wearing a heavy prosthesis, or under wire support.
17. If you live in a damp or humid climate, and your skin is frequently moist, try dusting the skin with cornstarch. This also works for feet during the summer months. Keeping the skin dry helps reduce fungi.
18. Maintain your ideal weight and drink plenty of pure water. The recommended quantity of water is one ounce for every two pounds of bodyweight. Example: If you weigh 128 pounds, drink 64 ounces or two quarts of water daily. If you do not normally drink this much water, increase intake gradually until the recommended quantity is achieved.
19. Many patients have a misunderstanding about protein. They believe that because lymphedema is a high protein edema, they should avoid eating protein. This is not true. While we do not recommend a high protein diet, a no protein diet will weaken connective tissues and cells. This in turn will make the condition worse. We recommend a diet in which easily digestible proteins make up between 10 and 30 percent of your total caloric intake. Know when to get help.
20. It can be helpful to have a professional assessment annually. If you have a leg at risk, visiting  can insure that your feet stay healthy. Be sure to inform him or her that you are at risk for developing lymphedema.
21. MLD, manual lymph drainage, is a recognized therapy not only as a treatment for lymphedema, but for prevention as well. If you have had lymph nodes removed, your immune system is compromised. MLD helps to increase immune response. Other forms of massage therapy should be avoided on the at-risk quadrant, because they temporarily shut down the lymph vessels in that area. These include deep tissue, reflexology, Rolfing, shiatsu, Swedish, etc.
22. Thoroughly examine the affected quadrant monthly. Do not ignore any swelling in the affected arm, leg, chest wall, armpit, back, groin, abdomen or genitals. Report any swelling immediately or if any of the following are present; redness, inflammation, blistering, rash, warmth in the limb, fever, change in the texture of the skin, or lymph leakage through the skin, see your oncologist or physician immediately. Any of these can be the onset or worsening of lymphedema.
23. The lymph system is an important part of your immune system, and removal of lymph nodes compromises your immune response in the at risk quadrant. If you get a cut, scrape, or other break in the skin, use a topical

antibiotic, and notify your physician at once. He or she will probably prescribe an antibiotic to reduce your risk of developing an infection. Remember, an infection in an at-risk limb or quadrant can lead to the onset of lymphedema if it is not treated promptly.

24. Lymphedema is often preventable, or at least can be postponed for many years. If you notice any slight increase in swelling of your fingers, hand, arm, chest wall, back, toes, feet, ankles, abdomen or genitals, see your physician for a proper diagnosis. If you are diagnosed with lymphedema, seek treatment. Lymphedema is easier to control at its onset, as further deterioration can be prevented and often an initial reversal is possible. Your limb will still be at risk, but you will remain symptom free. Remember what renowned lymphologist Dr. Foldi has written, “There is no insignificant swelling.”

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MSU LYMPHEDEMA CLINIC Also Recommends the Following

Controlling Lymphedema of the Arm	Controlling Lymphedema of the Leg
<p>At risk is anyone who has had either a simple mastectomy, lumpectomy or modified radical mastectomy in combination with axillary node dissection and, often, radiation therapy. Lymphedema can occur immediately postoperatively, within a few months, a couple of years, or 20 years or more after cancer therapy. With proper education and care, lymphedema can sometimes be avoided or if it develops, kept well under control.</p>	<p>At risk are those who have undergone cancer treatment that involves surgery, lymph node dissection and/or radiation; Individuals who have a history of cellulitis or deep vein thrombosis; Traumatic events particularly severe or multiple events; and Orthopedic surgery, especially those who have a history of venous stasis. Lymphedema can also be obesity generated. As with the arm, Lymphedema can sometimes be avoided, or if it develops, kept well under control.</p>
<p><u>Garment</u></p> <ul style="list-style-type: none"> • Patients who have lymphedema should wear a well-fitted compression sleeve during all waking hours. If indicated follow-up with your therapist every six months (you will need a physician referral). If the sleeve is too loose, most likely the arm circumference has reduced or the sleeve is worn. A compression bandage should be worn at night. A well-fitting sleeve is essential in controlling swelling. 	<p><u>Garment</u></p> <ul style="list-style-type: none"> • Patients who have lymphedema should wear a well-fitted compression sleeve during all waking hours. If indicated follow-up with your therapist every six months (you will need a physician referral). If the sleeve is too loose, most likely the leg circumference has reduced or the sleeve is worn. A compression bandage should be worn at night. A well-fitting sleeve is essential in controlling swelling.
Controlling Lymphedema of the Arm (cont'd)	Controlling Lymphedema of the Leg



Infections

- If you notice a rash, blistering, redness, increase of temperature, fever or chills, see your physician immediately. An inflammation or infection (cellulitis) in the arm could be the beginning of lymphedema or a worsening of lymphedema. A cellulitis infection can quickly spread and should be treated quickly. Any break in the skin, if left untreated, can cause an infection.
- Use caution when playing with pets. Scratches and bites can become infected.
- Take precautions to avoid insect bites. A simple mosquito bite can cause cellulitis (erysipelas) and further increase the size of your arm. Wear an insect repellent when outdoors.

Range of Motion/Positioning

- Avoid letting your arm hang down for long periods.
- Avoid lying on your arms.
- Avoid keeping your arm in bent position for long periods of time.
- If you work in an office, take frequent breaks to stretch and move your arms. Repetitive movements, (i.e. computer) can cause retention of fluids in your arm.
- Elevate the affected arm at night.

General

- Do your lymphedema exercises regularly
- Watches and rings should fit comfortably and not be worn for long periods of time on the affected arm.
- When possible wear natural materials instead of synthetics, which can cause excessive heat and perspiration.
- Avoid heavy lifting with the affected arm. Never carry heavy handbags or bags with over-the-shoulder straps. Do not lift more than 10-15 lbs.
- If you smoke, do not hold the cigarette with the hand of your affected arm
- The affected arm should not be exposed to:
 - hot packs, moist heat, hot tubs, saunas, ice packs
 - deep tissue massage
 - cosmetics/lotions which could irritate the skin

Infections

- If you notice a rash, blistering, redness, increase of temperature, fever or chills, see your physician immediately. An inflammation or infection (cellulitis) in the leg could be the beginning of lymphedema or a worsening of lymphedema. A cellulitis infection can quickly spread and should be treated quickly. Any break in the skin, if left untreated, can cause an infection.
- Use caution when playing with pets. Scratches and bites can become infected.
- Take precautions to avoid insect bites. A simple mosquito bite can cause cellulitis (erysipelas) and further increase the size of your arm. Wear an insect repellent when outdoors.
- Do not use a razor or any sharp instrument to cut corns or calluses when caring for your feet. Use a nail file carefully when filing toenails and a pumice stone to loosen dead skin.
- Do not walk barefoot.

Range of Motion/Positioning

- Avoid long periods of sitting and standing; lying down and walking are better. When you do sit, do not cross your legs.
- Through the day take time to elevate your leg for a few minutes. Elevation helps promote the drainage of fluid from your leg. When elevating, make sure your leg is above the heart.

General

- Do your lymphedema exercises regularly. Use caution when doing exercises or participating in sporting activities. Avoid movements that overstrain or put extra weight on the muscles. Walking is an excellent exercise with the proper footwear and the compression stocking. Swimming is another excellent exercise and does not cause stress on the joints.
- When possible wear natural materials instead of synthetics, which can cause excessive heat and perspiration
- The affected limb should not be exposed to:
 - hot packs, moist heat, hot tubs, saunas, ice packs
 - deep tissue massage
 - lotions which could irritate the skin

