

Lymphedema Risk Reduction Practices

By the NLN Medical Advisory Committee; May2012

Lymphedema is the accumulation of protein-rich fluid in tissues with inadequate lymphatic drainage. It is not known why some people with the same risk factors develop lymphedema and others do not. An underlying predisposition to developing lymphedema may be a contributing factor.^{1, 2, 3} Scientific evidence is lacking regarding risk reduction practices^{4, 5}, how to reduce the risk of developing lymphedema, or how to minimize flares of lymphedema.

Many recommendations for risk reduction are common sense approaches based on the body's anatomy and physiology. Because of individual variations in anatomy and because lymphedema may be caused by many different factors, each person with lymphedema or at risk for lymphedema needs to have their risk-reduction practices individualized. What works for one person may not work for another.

Based on practical experience, there are some reasonable actions and precautions to be taken for individuals with or at risk for lymphedema. Lymphedema is a progressive condition without a cure; caution should be exercised to reduce the risk of developing or exacerbating lymphedema.

This position paper provides information to assist the person with or at risk for lymphedema to make the best possible and most informed choices about risk-reduction practices.

If you are not clear about your own risks, meet with a treatment provider who is knowledgeable about lymphedema to discuss your personal strategies for risk reduction.

This paper differentiates people with a confirmed diagnosis of lymphedema⁶ from people at risk of lymphedema. People at risk of lymphedema are individuals who have not yet displayed the signs and symptoms of lymphedema but have a known insufficiency of their lymphatic system. This includes people who have undergone removal of lymph nodes or radiation therapy, which increases the risk for developing lymphedema. At-risk individuals have altered lymphatic function that may impede the body's ability to take up excess fluids in the tissues.

People with a **confirmed diagnosis of lymphedema** should consider the following actions and precautions:

1. **Medical check-ups:** Have regular follow-ups by professionals with training in lymphedema. The follow-up schedule should be based on your individual situation and determined by your lymphedema care provider.
2. **Reporting changes:** Report to your health care provider any change in your lymphedema, such as increase in size, change in sensation, color, temperature, or skin condition. If your weight or size of lymphedema body part changes, seek assistance from a lymphedema professional to determine if a new course of therapy or new garment is needed.
3. **Body weight:** Obesity is known to be a major risk factor for lymphedema^{7, 8, 9}. A person with lymphedema should maintain a normal body weight and seek professional help to lose weight if your weight is above standard recommended guidelines. In one study, lymphedema treatment was more effective if combined with weight loss.¹⁰ People who

do not know their recommended weight for age and height should seek information from a health care provider.

4. **Exercise:** Follow recommendations on exercise for lymphedema¹¹, as specific forms of exercise have been shown to benefit lymphedema.¹² Incorrect or unsafe exercise may exacerbate lymphedema.¹¹

5. **Compression garments:** If you wear compression garments for control of lymphedema, follow the manufacturer's care recommendations. Replace the garment as recommended. Wear your usual compression garments for air travel, exercise, and exertion.^{11, 13}

6. **Infections (cellulitis):** Treat all episodes of cellulitis (infection in subcutaneous tissue) as an urgent medical situation. Know the signs and symptoms of cellulitis skin infection in an area of impaired lymph drainage (signs may include redness, warmth, pain, fever, and feeling of overall illness or flu-like symptoms).¹⁴ Cellulitis episodes may lead to worsening lymphedema.¹⁵ If you have more than three episodes of cellulitis in a year, discuss with a health care provider whether your situation warrants using suppressive antibiotics.^{14, 16}

7. **Skin care:** Maintain skin in good condition¹⁷ with proper hygiene. Regularly use a moisturizer to avoid skin cracking. If you wear garments, ask your fitter or the manufacturer for information on whether you can use lotion with your garments and what type of lotion is best. Some lotions affect the fibers of compression garments.

8. **Trauma:** Avoid trauma to the affected area.¹⁵ Trauma includes any situation that might typically cause swelling in a person without lymphedema, but may lead to prolonged swelling in the area of impaired lymphatic drainage.

- a. Protect against falls, fractures, and serious burns.^{18, 19} If any of these occur, perform first aid or seek emergency care as appropriate. After the emergency is controlled, if there is prolonged edema, contact a lymphedema provider.
- b. If required to have venipuncture, inform the

phlebotomist of your lymphedema, and use a non-lymphedema limb, if possible.²⁰ If not possible, inform the phlebotomist of your lymphedema condition and ask for the most experienced phlebotomist. Do not allow multiple or traumatic searches for veins, which can increase tissue edema. If a traumatic venipuncture occurs on a lymphedema extremity, immediately wash the area, apply a cold pack, then elevate until edema subsides. If it does not subside in 24 hours, contact your lymphedema provider.

- c. For scratches, punctures, breaks in the skin of the lymphedema part, wash with soap and water, pat dry, then apply a topical antibacterial.
- d. Wear non-constricting protective gear over the affected part when doing an activity that could lead to puncture or trauma, e.g., shoes and socks, protective gloves or sleeves when gardening or working with animals that scratch or bite. Ask your lymphedema provider for specifics for your lymphedema.
- e. Nail care may need to be done by professionals, especially toenails. For leg lymphedema, toenails may need to be trimmed by a podiatrist. Fungal infections should be treated and foot hygiene maintained.
For arm lymphedema, good hand hygiene and softening the cuticles with proper cuticle moisturizer is recommended. Be careful with manicures; use clean instruments and avoid cutting cuticles.

9. **Constriction:** Avoid excessive or prolonged constriction of the affected part. Excessive constriction refers to tightening or squeezing in a manner that restricts lymph flow through that area or causes tissue trauma. Examples of excessive constriction include improperly fitting compression garments and clothing (tight sleeves on a lymphedema arm, tight stockings on a lymphedema leg, tight bra, or excessive pressure from an underwire on chest or breast lymphedema). Clothing and garments should be supportive and have smooth compression. Blood pressure cuffs used improperly or

with extreme pressure may excessively constrict tissues (see controversies below).

10. **Heat and cold:** Avoid exposure to extreme heat or cold¹⁵ to the extent that tissue injury could occur such as burn or frostbite (see controversies below).
11. **Surgery:** If you need to have surgery on an area with lymphedema, inform your surgeon of your lymphedema condition. You may wish to meet with a lymphedema provider prior to your surgery to have a post-operative lymphedema care plan in case the lymphedema worsens after surgery. If lymphedema does not worsen after surgery, resume your prior care of lymphedema.
12. **Stasis:** People with leg lymphedema should avoid conditions which cause stasis. Stasis refers to sitting or standing for a long period of time without moving, changing position, or elevating the legs. In a survey study of 89 women with confirmed lymphedema after gynecologic cancer, 46 percent identified prolonged sitting in one position or standing as a major factor exacerbating lymphedema.¹⁵ Many people who do not have lymphedema experience swelling in the legs with conditions of stasis. It is a theoretical greater risk for people who have impaired lymphatic drainage that may not be able to remove excess accumulated fluid in the legs due to prolonged sitting and standing. Moving, changing position, and exercising periodically throughout the day are recommended for people with leg lymphedema.
13. **Varicose veins:** People with leg lymphedema who also have varicose veins need to check with a health care provider to determine if varicose vein treatment is recommended. For some individuals with lymphedema, treating varicose veins can reduce the lymphatic load of fluid in the tissues and improve the lymphedema management.
14. **Air Travel:** Air travel is associated with a risk of venous thromboembolism (blood clot in the veins, or VTE) on long flights for people with and without lymphedema.¹³ The risk of VTE from long-haul air travel is believed to be caused by low cabin pressure combined with lowered oxygen levels, dehydration,

and lack of movement. It is unclear whether people with lymphedema have more risk of VTE than the general population (see controversies below). In one study of 89 gynecologic cancer survivors, stasis and air travel were associated with flares of leg lymphedema.¹⁵ It is recommended for people with lymphedema to wear their usual compression garments for air travel. It is equally as important to move around, exercise the affected body part, and maintain good hydration during air travel.

People **at-risk for developing lymphedema** should consider the following actions and precautions:

1. **Medical check-ups:** Medical check-ups or screening for lymphedema is recommended.²¹ Individuals at risk for breast cancer-related lymphedema should follow the recommendations outlined in the National Lymphedema Network's Position Paper on Screening and Measurement for Early Detection of Breast Cancer Related LE (BCRL).²¹ In other at-risk individuals, a follow-up schedule should be based on your individual situation and determined by your lymphedema care provider.
2. **Reporting changes:** Report to your health care provider any change in your at-risk body part, such as increase in size, change in sensation, color, temperature, or skin condition. Diagnosing and treating the onset of lymphedema at the earliest possible time improves outcomes.⁶
3. **Body weight:** Obesity is known to be a major risk factor for lymphedema^{7, 8, 9}. A person at risk for lymphedema should maintain a normal body weight and seek professional help to lose weight if their weight is above standard recommended guidelines. People who do not know their recommended weight for age and height should seek information from a health care provider.
4. **Exercise:** Follow recommendations on exercise for lymphedema,¹¹ as specific forms of exercise may reduce the risk of developing lymphedema.¹²

Incorrect or unsafe exercise may increase the risk of lymphedema.¹¹

5. **Compression garments:** Consider the pros and cons of wearing compression garments during air travel before making a decision (see controversies below). Wearing compression garments during exercise is probably unnecessary unless you have noticed that swelling occurs during exercise, if exercise is more intense than usual, or in cases of significant over-activity.²² There is no clear guidance on this area of risk reduction; discuss your concerns with a lymphedema provider.
6. **Infections (cellulitis):** Treat all episodes of cellulitis (infection in subcutaneous tissue) in the at-risk body part as an urgent medical situation. Know the signs and symptoms of cellulitis skin infection in an area of impaired lymph drainage (signs may include redness, warmth, pain, fever, and feeling of overall illness or flu-like symptoms).¹⁴ Cellulitis episodes in the at-risk body part may lead to the onset of lymphedema.¹⁵
7. **Skin care:** Maintain skin in good condition¹⁷ with proper hygiene and regularly use a moisturizer to avoid skin cracking.
8. **Trauma:** Avoid trauma to the at-risk area.¹⁵ Trauma includes any situation that might typically cause swelling in a person without lymphedema, but may lead to prolonged swelling in the area of impaired lymphatic drainage.
 - a. Protect against falls, fractures, and serious burns. If any of these occur, perform first aid or seek emergency care as appropriate. After the emergency is controlled, if there is prolonged edema, contact a lymphedema provider.
 - b. If required to have venipuncture, inform the phlebotomist of your lymphedema risk and use a not-at-risk limb if possible.²⁰ If not possible, inform the phlebotomist of your lymphedema risk condition and ask for the most experienced phlebotomist. Do not allow multiple or traumatic searches for veins, which can increase tissue edema. If a traumatic venipuncture on an at-risk lymphedema extremity occurs, immediately wash the area, apply a cold pack, and then elevate until edema subsides. If it does not subside in 24 hours, contact your lymphedema provider.
- c. For scratches, punctures, breaks in the skin of the at-risk body part, wash with soap and water, pat dry, then apply a topical antibacterial.
- d. Wear non-constricting protective gear over the at-risk body part when doing an activity that could lead to puncture or trauma, e.g., shoes and socks, protective gloves or sleeves when gardening or working with animals that scratch or bite. Ask your lymphedema provider for specifics for your lymphedema.
- e. Consider having nail care done by professionals, especially toenails. For people with risk of leg lymphedema, toenails may need to be trimmed by a podiatrist. Fungal infections should be treated and foot hygiene maintained. For people at-risk for arm lymphedema, good hand hygiene and softening the cuticles with proper cuticle moisturizer is recommended. Be careful with manicures; use clean instruments and avoid cutting cuticles.
9. **Constriction:** Avoid excessive or prolonged constriction of the at-risk body part. Excessive constriction refers to tightening or squeezing in a manner that restricts lymph flow through that area or causes tissue trauma. Examples of excessive constriction include improperly fitting compression garments and clothing (tight sleeves on a lymphedema arm, tight stockings on a lymphedema leg, tight bra, or excessive pressure from an underwire on chest or breast lymphedema). Clothing and garments should be supportive and have smooth compression. Blood pressure cuffs used improperly or with extreme pressure may excessively constrict tissues (see controversies below).
10. **Heat and cold:** Avoid exposure to extreme heat or cold¹⁵ to the extent that tissue injury could occur, such as burn or frostbite (see controversies below).

11. **Surgery:** If you need to have surgery on an area at risk for lymphedema, inform your surgeon of your risk for lymphedema. Ask your surgeon how long swelling is usually present after your type of surgery. You may wish to meet with a lymphedema provider prior to your surgery to have a post-operative lymphedema care plan in case of prolonged or excessive post-operative swelling. After surgery, if you experience prolonged or excessive swelling, notify your surgeon and request a referral to a lymphedema provider.

12. **Stasis:** People at risk for leg lymphedema should avoid conditions which cause stasis. Stasis refers to sitting or standing for a long period of time without moving, changing position, or elevating the legs. It is unknown if stasis can precipitate the onset of lymphedema in the at-risk leg. Many people who do not have lymphedema experience swelling in the legs with conditions of stasis. Sitting or standing for too long an interval could theoretically increase the risk for lymphedema in people who have impaired lymphatic drainage. This is because an impaired lymphatic system may not be able to remove excess fluid in the legs that accumulates during these long periods of sitting or standing. Moving, changing position, and exercising periodically throughout the day are recommended for people at risk for lymphedema of the leg. In a survey study of 89 women with confirmed lymphedema after gynecologic cancer, 46 percent identified prolonged sitting in one position or standing as a major factor exacerbating lymphedema.¹⁵

13. **Varicose Veins:** For individuals at risk for leg lymphedema, varicose veins and postural swelling can be managed by wearing support stockings. If edema worsens, contact your health care provider.

14. **Air Travel:** Air travel is associated with a risk of venous thromboembolism (blood clot in veins, or VTE) on long flights for people with and without lymphedema.¹³ The risk of VTE from long-haul air travel is believed to be caused by low cabin pressure combined with lowered oxygen levels, dehydration, and lack of movement.¹³ It is not known whether people at risk for lymphedema have more risk of VTE

than the general population. The risk of precipitating the onset of lymphedema during air travel for people with lymphedema is unclear (see controversies below). It is recommended that people with lymphedema review the pros and cons of wearing prophylactic compression during air travel (detailed in the controversies section of this paper) and make an informed personal decision. Regardless of the use of prophylactic compression, it is important to move around, exercise the at-risk body part, and maintain good hydration during air travel.¹³

Controversies regarding risk reduction practices:

1. **Air travel:** There is little evidence that lymphedema is caused or worsened by air travel. There is a theoretical risk of swelling in the at-risk area on an airplane because of reduced cabin pressure. Stasis, or lack of movement, can cause swelling or venous blood clots during air travel for people with or without lymphedema.¹³ There are isolated case reports of people with or at risk for lymphedema who have developed swelling after air travel.^{23, 15} One study showed that physically fit women at risk for breast cancer-related lymphedema had no increase in swelling from air travel.²⁴ Another study showed that prophylactic compression had the potential to make swelling worse.²⁵ The NLN cannot specifically recommend or not recommend compression garments for prophylaxis in at-risk people who have not yet developed lymphedema. People at risk for lymphedema who decide to wear prophylactic compression on airplanes should work with an experienced garment fitter and should not self-purchase a garment. The person who chooses to wear prophylactic compression on an airplane should wear the garment several times prior to air travel to make sure the garment fits well and has no areas of constriction. If, while wearing a garment on an airplane, the swelling increases or the garment constricts, remove it immediately. It is recommended that people with a confirmed diagnosis of lymphedema wear properly fitting compression garments for air travel.

2. **Blood pressure cuffs:** Studies have not determined

the actual risk of having BP taken on the at-risk arm. Some feel that an isolated, low-pressure, and brief BP assessment is unlikely to cause or worsen lymphedema. Some authors have claimed that because compression is used for lymphedema treatment, BP cuffs and air compression devices are safe.^{5, 26} This is an erroneous conclusion due to the following

considerations: a. Pneumatic compression devices used for lymphedema treatment are sequential, gradient compression; b. BP cuffs and tourniquets are high pressure focal compression that can lead to excessive constriction if not properly used; c. User-error with high-pressure BP machines repetitively cycling is quite different from a hand BP device pumped up to just a little higher than the usual upper level BP. Because lymphedema is a serious and progressive condition, if possible, use an uninvolved or not-at-risk extremity when taking blood pressure. In doctors' offices or hospitals, where machine BPs are regularly taken, the patient can request a hand BP measurement and have the medical provider only pump the cuff to just a little above the usual BP, thereby avoiding repetitive pumping or painful squeezing.

3. **Mammograms:** There is no evidence that mammograms cause or worsen breast lymphedema. If you have concerns about breast tenderness, swelling, or soreness after a mammogram on a breast with or at risk for lymphedema, discuss the issue with your radiology technician or health care provider.
4. **Razors:** There is no evidence that shaving with a clean razor on clean skin causes or increases lymphedema. However, a common sense approach is as follows: when shaving an area with no feeling or that you cannot see, be very cautious and watch what you are doing directly or in a mirror. Do not shave dry skin or use rusty razors that can cause trauma to skin. Do not shave areas of severe lymphedema that have large skin folds, wounds, or deep creases.

5. **Heat and cold:** There is conflicting evidence on the risk of excessive heat or cold and lymphedema. Based on one survey study of gynecologic cancer survivors, legs may be more at risk than arms with exposure to heat.¹⁵ Individuals should use common sense, proceed very cautiously when using heat or cold therapy, and limit the length of exposure until you know the response of your at-risk body part. Monitor closely the effect of any change in environmental condition on your at-risk body part, and stop if there is increased swelling from exposure to extreme heat or cold. There is a theoretical risk of worsening the lymphedema if the heat or cold is extreme or long enough to cause tissue damage. There is a theoretical risk of immersion moist heat (sauna, hot tub) when done to the point of raising body temperature. Topical heat may or may not have a positive or negative effect on lymphedema.^{27,28,29}

6. **Hospitals, doctor's offices and medical facilities:** Medical facilities should have a written policy regarding the at-risk limb. Since many patients have varying levels of risk for lymphedema that cannot easily be determined, the facility should make a reasonable attempt to protect any limb the patient identifies as being at risk for lymphedema. Some medical professionals are unfamiliar with lymphedema and might not take reasonable precautions unless there is a policy. The ability of phlebotomists and professionals using tourniquets or BP machines varies. It is reasonable for an individual with or at risk of lymphedema to have his or her concern properly addressed by health care professionals and facilities. In a medical emergency or when there is no uninvolved limb, health care facilities should address the medical priority, but take reasonable precaution with venipuncture and BP limb constriction to an area of impaired lymphatic drainage. If swelling occurs in an area of impaired lymphatic drainage after a procedure, the provider should give care instructions to the patient.

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