

what you should know about
Lymphedema



The lymph system is a network of nodes and vessels that carry clear lymph fluid through the body to filter out harmful substances and fight infections. Lymphedema is the build-up of lymph fluid in the fatty tissue under the skin. This causes swelling (edema), often in the arms and legs.

Lymphedema can be either **primary** or **secondary**. Primary lymphedema is caused by problems with the way the lymph system formed and is present at birth. Secondary lymphedema is often caused by injury, radiation treatment, or surgery to remove lymph nodes and nearby tissue. This can cause problems with the way lymph fluid drains in the body.

Your physician, therapist, or nurse can explain your risk for lymphedema.

Lymphedema is not caused or made worse by a single event. Many factors combine to cause the problem. You cannot control some factors, such as cancer, injury, or problems with your body's lymph system. You can control some other factors discussed in this booklet. This can help you manage or delay the onset of lymphedema.

The information in this booklet is drawn from the experience of Kaiser Permanente staff as well as tips and advice from the National Lymphedema Network and the American Cancer Society.



Clothing

- Avoid all tight clothing, elastic bands, and jewelry, or anything that binds or leaves marks on the affected limb.
- Avoid bras that cut into your shoulders or bind too tightly around the middle. Wear soft pads under your bra straps. Avoid bras with underwires. Tight straps and underwires may block the flow of lymph fluid.
- Wear as light a prosthesis (breast form) as possible.
- Do not carry a heavy purse or bag on the affected shoulder.
- Wrist watches and rings should fit loosely and should not be worn for long times on the affected arm.

Overheating

- Be very careful when exercising in hot weather.
- Drink plenty of water to stay hydrated.
- Avoid hot tubs, steam baths, saunas, hot packs, and very hot baths or showers.
- Protect the affected area from weather extremes:
 - In hot weather, stay in air-conditioned rooms and keep the limb cool.
 - In cold weather, stay in rooms with central heating. If you must go out, have the affected area bundled but not sweaty.
 - In sunny weather, protect the limb with sunscreen and/or by covering it.

Exercise and Activity: Moderation Is the Key

- Use caution with repeated movements; avoid heavy lifting, pushing, or pulling.
- Light to moderate exercise every day can be very helpful. If starting a new exercise program, ease into it slowly. Do not overdo it!
- Walking, swimming, or water exercises are fine.
- If you have lymphedema, bandage the limb when exercising.
- If the limb begins to ache or feel tired, rest and raise the limb if possible.
- Avoid heavy lifting or carrying heavy items, such as a briefcase or suitcase, with your arm hanging down at your side for a long time.
- Don't have deep tissue massage, reflexology, Rolfing, shiatsu, or Swedish massage on the affected area.



Skin Care

- Keep the entire affected area clean. Natural gentle cleansing products with a low pH are best. One example is Aveeno oatmeal-based products. Dry the skin gently but thoroughly. Be sure to dry the creases in the skin and between the toes and fingers.
- Use a top-quality, low pH moisturizing lotion for your skin. Choose a lotion without alcohol, dyes, mineral oil, petroleum products, talc, or perfumes.
- Suggested products are Eucerin, Curel, Dermal Therapy, and Johnson & Johnson Baby Lotion. Alpha hydroxy acid lotions such as Eucerin Plus or Lac-Hydrin Five can also be used. You may be able to find store brand versions of some of these lotions. Apply the lotion after bathing or before and after taking off compression bandages and garments if you have lymphedema.
- If you live in a damp or humid climate and your skin is often moist, dust your skin with cornstarch or powder. This works well for the feet during the summer. Keeping your skin dry helps reduce fungal infections.
- If you shave under your arms, use a well-maintained electric razor. Because of the danger of nicks and cuts, a regular safety razor may not be safe. If you do use one, wash the blades in hot, soapy water after use and replace them often. Treat any nicks with an antibiotic cream such as Polysporin or bacitracin.
- Make sure all fabrics that touch your skin are washed often. This includes compression bandages and garments. Ask your therapist how to care for these items.
- Avoid extreme temperature changes when:
 - Bathing, showering, swimming
 - Washing dishes, floors, laundry, etc.
 - Having therapy treatments
 - At the gym—do not use the sauna or hot tub

- Protect yourself from sunburn by using a sunscreen or a cover.
- When possible, have injections, blood pressure measurements, blood draws, allergy tests, and acupuncture on an unaffected limb. A leg can often be used if both arms are affected.
- Be careful when cutting your nails. Do not nick the skin or cut your cuticles. If you have your nails done at a salon, tell the staff to be careful. Check to be sure the salon is clean.
- Protect your limb from injury and infection. Cuts, scrapes, bruises, burns, sports injuries, insect bites, pet bites, and scratches can become infected.
 - Use oven mitts when removing hot pans from the oven.
 - Wear insect repellent or long sleeves when outdoors.
 - Wear rubber gloves when washing dishes or floors or using cleaners or chemicals.
 - Wear gloves while gardening.
 - Wear closed-toed shoes.
 - Keep your pets' nails well trimmed to avoid scratches.
- Check your skin each day for cuts, burns, bites, hangnails, and cracked or torn cuticles. Treat all breaks in the skin with antibacterial ointment and a bandage.



Know the signs of infection:

- Redness
- Warmth
- Tenderness
- Red streaks
- More swelling

Your lymphatic system is already overloaded and an infection will increase swelling in the area. Also, with a decreased immune system response, infections can get worse quickly and heal slowly. **Call your physician or other health care professional right away.**

Healthy Eating

- Eat a balanced, healthy diet that includes plenty of vegetables, fruits, whole grains, and some lean protein. A high-protein diet is not recommended for people with lymphedema.
- Maintain your weight or move toward a healthy weight with healthy eating and regular exercise. Being overweight increases your chances of having lymphedema and makes it harder to manage. Kaiser Permanente offers many weight management programs, including one-session overview classes, weekly group programs, and meal replacement programs. Check with your local Kaiser Permanente Health Education Department or visit kp.org/classes.
- Drink at least 8 to 10 eight-ounce glasses of water each day. Drink more in warm weather and when you exercise.

Air Travel

- Decreased cabin pressure in airplanes may increase your chances of developing lymphedema or may make it worse. Research has not yet proven the link between air travel and lymphedema, yet many people have reported the onset of lymphedema after air travel.
- If you have lymphedema and will be flying or hiking in high altitudes, you should wear a compression garment or low-stretch bandages. For an affected limb, you can buy low-cost compression garments over the counter. If you have lymphedema, bandages offer more protection than a compression garment. See your therapist for advice on getting or buying bandages.
- Move your arm often, bending and straightening your elbow, wrist, and fingers.
- Get up and move around when the “fasten seat belt” sign is off.
- Be sure to drink plenty of water.



Final Tips

Examine the affected area very carefully every month. **Do not ignore any swelling** in the affected arm, leg, chest wall, armpit, back, groin, abdomen, or genitals.

If you have redness, inflammation, blistering, rash, warmth in the limb, fever, change in skin texture, or lymph leakage through the skin, see your physician or other health care professional right away.

If you are diagnosed with lymphedema, seek treatment right away. Lymphedema is easier to control at an early stage. With treatment, symptoms can often be prevented and managed.

For More Information

Visit the National Lymphedema Network website at lymphnet.org.

Notes

*Kaiser Permanente does not endorse the medications or products mentioned.
Any trade names listed are for easy identification only.*



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SCMPG Regional Health Education
MH0758 (5/13)
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