

Common Questions About Breast Cancer-Related Lymphedema

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What is lymphedema?

Lymphedema related to treatment for breast cancer is an abnormal swelling of the arm or hand. Some patients also report swelling in the breast or chest wall.

Who gets lymphedema?

There have been many studies of arm lymphedema after lymph node removal for breast cancer. The risk of developing lymphedema varies based on how the lymph nodes are removed.

- **Sentinel lymph node biopsy.** Studies show the risk of developing lymphedema is very, very low. As few as 0 to 7 out of every 100 patients will develop lymphedema.
- **Axillary lymph node dissection.** Studies show the risk of developing lymphedema is higher. About 15 to 25 out of every 100 patients will develop lymphedema.

In one study, half of the women who had an axillary lymph node dissection said they felt arm swelling even 20 years later. However, since cancer treatments have improved, fewer patients now develop lymphedema.

Lymphedema occurs when the arm's lymph vessels are no longer able to carry all the fluid out of the arm. Lymph vessels also carry bacteria away from the arm. Studies have shown that patients who have the highest risk of getting lymphedema:

- Had radiation to the axilla (or armpit).
- Had an infection in the arm or chest on the side of the surgery.
- Had a severe injury (such as a serious burn or wound) in the area of the surgery.

Other risk factors include:

- Recurrent breast cancer that blocks the flow of lymph fluid.
- Being overweight or gaining weight after treatment.

Whether or not you have swelling depends on your body's response to the treatments you received.

When might I get lymphedema?

Lymphedema can occur soon after surgery. It can also begin months or years later. Your arm might start to swell because of an injury to the arm. But often, the only obvious reason the arm starts to swell is having had breast cancer treatment.

What can I do to minimize my risk of developing lymphedema?

We do not know if any activities increase the risk of having lymphedema after breast cancer. However, we recommend that you take some precautions. We hope these will lower your risk.

- Avoid anything that might cause a break in the skin, which can lead to an infection. If you do get a cut on your arm or hand, clean the area well and apply anti-bacterial ointment. Cover it with a bandage.
- Be cautious about shaving under your arm on the side of the surgery.
- Manicure your nails carefully. Push your cuticles back instead of cutting them.
- Use a moisturizer daily to help protect the skin of your arm and hand.
- Use insect repellent to avoid stings.
- Wear gloves when gardening, cleaning, or washing dishes.
- If you notice any swelling in your affected arm or hand, remove:
 - Tight or heavy jewelry.
 - Clothing that has tight elastic and leaves a mark on your arm.
- Avoid heating pads and hot-packs on your affected arm and shoulder.
- Take care not to get sunburned. Use sunblock with an SPF of at least 30. Reapply often.
- Try to use your unaffected arm for injections, blood drawings, and blood pressure measurements. If both sides had lymph nodes removed, talk with your doctor about which arm would be safest to use.
- Try to maintain your normal weight or safely work towards a more ideal body weight.
- Exercise and stretch your muscles on a regular basis. Avoid overworking your body.

May I resume all of my prior activities and exercise routines?

Recent studies have suggested that exercise, including weight lifting, is safe for women with lymphedema. It may actually help reduce the swelling. There is no limit on the amount of weight; however adding weight should be **gradual and progressive**. If you already have swelling in your arm or hand, resistive exercise should be performed while using properly fitting compression garments or bandages. You may need to modify your exercise routine if you notice discomfort or more swelling while exercising.

We encourage you to continue all of the activities that give you pleasure. Research has shown that no activity level, occupation, or hobby is related to developing lymphedema. You should resume any hobby or a sport **slowly and gradually**. If you already have swelling in your arm or hand, doing repetitive activities, vigorous house cleaning, or sports should be performed while using properly fitting compression garments or bandages. You may choose to modify an activity if you notice that it causes more swelling or discomfort in your arm. Speak with your doctor and a trained therapist for help in modifying your exercises or activities.

How will I know if I have lymphedema?

Swelling that occurs right after surgery is common. It usually resolves with time. It does not mean that you have lymphedema or will develop it.

You may have lymphedema if you have swelling in your arm, hand, breast, or chest wall along with one or more of the follow symptoms:

- A feeling of heaviness, aching, or pain on the side of the surgery
- The skin of your arm, hand, or breast feels tight
- Your arm becomes tired more quickly than usual

Patients often notice lymphedema for the first time during or just after one of the following events:

- Injury
- Infection
- Burn
- Strenuous activity
- Significant weight gain
- Air travel (because of pressure changes)

These are probably not the cause of lymphedema. Rather, they may be “the last straw” that makes the swelling noticeable. This initial swelling may get better or even go away in a day or two. Still, the swelling is significant and you should let your doctor know about it.

What should I do if I think I have lymphedema?

If you notice that your arm is swollen, painful, red, or warm, call your doctor right away. It is important to let your doctor know about these symptoms even if they go away. An infection in the affected arm or breast is serious because it may progress quickly.

If an infection is present, it will be treated with antibiotics. More testing may be necessary. Your doctor may order an ultrasound of your arm. This test looks for blood clots. You may also need an MRI of the shoulder area to make sure there is no recurrent cancer.

Mostly, lymphedema is mild, treatable, and not a major impairment to quality of life. Evaluation, education, and treatment are important to help keep it that way.

What is the treatment for lymphedema?

Treatment for lymphedema can be simple or intensive. A trained therapist can help you choose the best program for you.

Treatment has four main components:

- Instruction in skin care – The precautions listed earlier are examples of ways you can take care of your skin.
- Compression – Compression helps prevent more fluid from building up in the tissue. It can be applied in the form of an elastic garment, low-stretch compression bandages, or other inelastic compression garments that are often used at night.

- Exercise – An exercise program helps to stimulate the lymph vessels. It is important to **slowly** increase the exercise so that the muscles of the arm do not become overly tired.
- A gentle form of massage called Manual Lymphatic Drainage (MLD) – Vigorous massage may cause fluid production. Avoid it on the affected arm and hand.

You should work with your doctor and therapist to set up a treatment plan. The plan should take into account your lifestyle and preferences. It takes time to figure out the best plan to keep the swelling under control. Talk with your therapist about any problems you have with your treatment. She or he can help you change your treatment plan so it works better for you.

Will the swelling ever go away?

Lymphedema is a chronic condition. The swelling may remain mild and stable, or it may worsen over time. There is no way to predict what will occur. Its course varies from person to person. Taking part in a treatment program to manage the swelling will help keep it under control. For those who are overweight, it is possible that weight loss may reduce the amount of swelling.

Are there any medicines I can take to reduce the swelling?

The answer is no. Water pills should not be used to manage lymphedema on a long-term basis. A drug called coumarin has been studied in Australia and Europe. It is different from the blood thinner Coumadin®. While some early studies reported that it was effective, newer and better designed studies found it had no benefit. It may even have toxic effects on the liver. This drug is not available in the United States. Antibiotics are used to treat acute and chronic infections. They have no direct effect on the lymphedema.

What precautions should I take to prevent worsening of my lymphedema?

Follow the precautions listed earlier. Those listed below may help prevent it from getting worse.

- Elevate the affected arm and hand. This may temporarily reduce the swelling, especially if the swelling is new. If you are sitting, rest the affected arm on a few pillows next to you or on the back of a couch. Your arm should be above the level of your heart. Do not hold your arm over your head for extended periods of time. That may cause the muscles of your arm to fatigue. If you sleep on your back, rest your arm on one or two pillows at your side. If you are able to sleep on the opposite side of your surgery, place one or two pillows in front of you. Rest your arm on those pillows. Over time, raising your arm may be less effective at reducing the swelling.
- Notice when your arm becomes more swollen and less swollen. Is the swelling worse in the morning after sleeping? Or is it worse in the evening after using your arm all day? Pay attention to what you do with your arm. If something you do makes your arm uncomfortable or swollen, take rest breaks when you do it. Some people find that using the arm helps reduce the swelling. Other people find that activities increase their swelling. Pay attention to things like carrying heavy bags, typing, or chopping vegetables.
- Use compression garments or low-stretch lymphedema bandages when you take an airplane flight. Do not use Ace bandages. Use some form of hand compression when you fly, even if you use a garment that ends at your wrist at other times. Make sure the garments fit well. They should be comfortable for you so you can keep them on for the entire length of the flight. If you are using compression garments for the first time, you may want to test them before your flight. That way, you can check that they do not cause any new swelling in your hand or arm. Low-stretch lymphedema bandages can be used instead of garments. Bandages are more bulky than garments and more difficult to apply, but they may be more comfortable for longer flights. They provide

excellent support to the lymphatic system if they are put on properly. Have your occupational or physical therapist show you how to apply them.

How do I cope with my feelings about having a diagnosis of lymphedema?

It is common to feel anger and frustration when you learn that you have lymphedema. Some people feel depressed. If you are having trouble coping with your feelings, tell your doctor or lymphedema therapist. Knowing that you have choices in treatment may help give you a sense of control. A lymphedema therapist can explain your options and help you decide on a treatment plan that will fit into your lifestyle. The swelling can usually be controlled with proper treatment.

What are the potential complications of lymphedema?

- **Infections** tend to be more serious in patients with lymphedema. They can be harder to treat, and progress more quickly. Infection in the affected arm can make the lymphedema worse. Patients should contact their doctor at the first sign of infection. These signs include:

- Fever or chills.
- Pain.
- Redness or warmth.
- Increased swelling.

Some people have repeated infections. If this happens to you, ask your doctor if you should see an infectious disease specialist.

- **Pain** or abnormal sensations can develop for many reasons. Not all of these are the result of lymphedema. Lymphedema can increase your risk for other disorders that cause pain. Speak to your doctor. After a diagnosis is made, proper treatment can be started.

Causes of arm pain include:

- Infection.
- The swelling itself.
- Deep vein thrombosis (DVT) or a blood clot in the vein.
- Other disorders such as:
 - Tendinitis of the shoulder.
 - “Golfer’s” or “tennis” elbow.
 - “Frozen shoulder”.
 - Carpal tunnel syndrome.
 - A pinched nerve in the neck.
 - Neuropathy (nerve sickness).

Conclusion

If you have any questions about lymphedema or you would like a referral to a lymphedema therapist, please speak with your doctor or nurse. You can also use the resources listed below.

Resources

National Lymphedema Network

Provides educational materials and community referrals.

Web site: www.lymphnet.org

Telephone: (415) 908-3681

Hotline: (800) 541-3259

American Cancer Society

Provides information about the diagnosis and treatment of lymphedema.

Web site: www.cancer.org

(800) 227-2345

Cancer Information Service (CIS)

Provides information about the diagnosis and treatment of lymphedema.

Web site: www.cancer.gov

1-800-4-CANCER

Step Up, Speak Out

Provides resources and educational materials about lymphedema

Web site: www.stepup-speakout.org

Notes



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