



PATIENT & CAREGIVER EDUCATION

Common Questions about Breast Cancer-Related Lymphedema

This information answers common questions about breast cancer-related lymphedema.

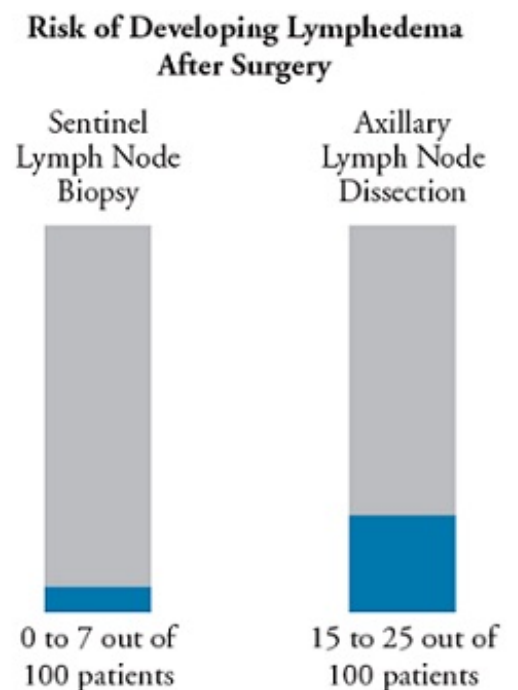
What is lymphedema?

Lymphedema is an abnormal swelling that can develop in the arm, hand, breast, or torso on the side where your lymph nodes were removed. This is called the affected side. Lymphedema develops when the lymph vessels in an area are no longer able to carry all the fluid away from the area. If this happens, the fluid can build up and cause swelling.

What puts me at risk for lymphedema?

Studies show that the risk of developing lymphedema is different based on how the lymph nodes were removed. There are 2 types of surgeries used to remove lymph nodes.

- **Sentinel lymph node biopsy:** between 1 and a few lymph nodes are removed from the armpit to check for cancer. With a sentinel lymph node biopsy, the risk of developing lymphedema is low.
- **Axillary lymph node dissection:** more lymph nodes are removed from the armpit. This is done to remove additional lymph nodes



that may have cancer. With an axillary lymph node dissection, the risk of developing lymphedema is higher than it is with a sentinel node biopsy.

Damage to your lymphatic system can also increase your risk of developing lymphedema. The following things can damage your lymphatic system:

- Radiation therapy to your armpit
- An infection after surgery
- Severe injury to your surgical area or the affected arm (such as a serious burn or wound)
- Tumor growth
- Weight gain after treatment, or being overweight

How long does it take for lymphedema to develop?

Lymphedema can develop suddenly or gradually. It can happen soon after surgery or can develop months or years later.

How can I lower my risk of developing lymphedema?

There is no way to know who will develop lymphedema, but there are things you can do that may lower your risk:

- Exercise and stretch your muscles on a regular basis. Don't overwork your body; if you feel discomfort, take a break.
- Maintain or safely work towards a healthy body weight.
- If you get a cut or scratch on your at-risk arm or hand, clean the area with soap and water and apply antibacterial ointment such as Bacitracin® or Neosporin®. Cover the area with a bandage.
- If you get a burn on your at-risk arm or hand, apply a cold pack or cold water for 15 minutes, clean the area with soap and water, and cover it with a bandage.

- Watch for signs of infection, including redness, swelling, increased heat, or tenderness.
- Blood draws and injections (shots) in your at-risk arm
 - If you had a sentinel lymph node biopsy, it's better to have your blood drawn and shots given on your arm that's not at risk for lymphedema. However, you can use your at-risk arm if needed.
 - If you had an axillary lymph node dissection, always use your arm that's not at risk, unless your doctor tells you it's okay.
 - If lymph nodes were removed on both sides of your body, talk with your doctor about which arm would be safest to use.
- Be careful not to get sunburned. Use sunblock with an SPF of at least 30. Reapply it often.
- Use insect repellent to avoid stings and bug bites.
- Use a lotion or cream daily to help protect the skin on your at-risk arm and hand. Don't use scissors to cut your cuticles; instead, push them back with a cuticle stick.
- Wear gloves when washing dishes, gardening, or cleaning with harsh detergent or steel wool.
- Be careful if you shave under your at-risk arm; consider using an electric razor. If you get a cut while shaving, take care of it following the instructions above.
- Don't use heating pads or hot-packs on your at-risk arm or shoulder.
- Take off any tight or heavy jewelry or clothing that has tight elastic and leaves a mark on your arm. These things can lead to swelling.

What are the signs of lymphedema?

Some mild swelling after surgery is normal. This swelling may last for up to 6 weeks, but it's temporary and will gradually go away. You may also feel pain or other sensations after surgery, such as twinges and tingling. These feelings are common and aren't necessarily signs of lymphedema.

The following are signs of lymphedema:

- A feeling of heaviness, aching, or pain on the side of your surgery
- A tight feeling in the skin of your arm, hand, or breast
- Decreased flexibility in your arm, hand, or fingers
- Swelling or changes in your skin, such as tightness or pitting (skin that stays indented after being pressed)

You may 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 events probably aren't the cause of the lymphedema, but they may make the swelling noticeable. This initial swelling may get better or even go away in 1 to 2 days.

What should I do if I think I have lymphedema?

Call your doctor if you notice that you have any signs of lymphedema. Look for signs of infection, such as your arm becoming swollen, painful, red, or warm. Call your doctor if you notice any of these signs, even if they go away. An infection in the arm or breast on your affected side is serious because it may get worse quickly. If you have an infection, your doctor may prescribe antibiotics or order more tests, such as an ultrasound or magnetic resonance imaging (MRI).

What is the treatment for lymphedema?

Treatment for lymphedema can be simple or intensive. An occupational or physical therapist who specializes in lymphedema can help choose the best program for you.

Treatment has 4 main components:

- **Skin care:** The suggestions listed earlier are examples of ways you can take care of your skin to prevent infections.
- **Compression:** Compression helps prevent more fluid from building up. It can be applied by wearing an elastic garment, low-stretch compression bandages, or other inelastic compression garments that are often used at night.
- **Exercise:** An exercise program can help stimulate your lymph vessels. It's important to slowly increase the exercise so that your arm muscles get used to it gradually.
- **Manual lymphatic drainage (MLD):** MLD is a gentle form of massage. Don't get a vigorous massage on your affected arm or hand because it can cause your body to make more fluid.

It takes time to figure out the best plan to keep the swelling under control. Talk with your lymphedema therapist about any problems you have with your treatment. They can help you change your treatment plan so it works better for you.

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

No. Water pills shouldn't be used to manage lymphedema. Antibiotics are used to treat short-term and chronic infections. They have no direct effect on the lymphedema.

Will the swelling ever go away?

The swelling may remain mild and stable, or it may get worse over time. There is no

way to predict what will happen. Taking part in a treatment program to manage the swelling will help keep it under control.

What can I do to prevent the lymphedema from getting worse?

Continue to follow the suggestions in this resource for lowering your risk of swelling or infection. Also, the suggestions listed below may help prevent it from getting worse.

- Elevate your affected arm and hand above the level of your heart. This may reduce the swelling for a period of time, especially if the swelling is new. Over time, you may find this doesn't work as well to reduce the swelling.
 - While you're sitting, rest your affected arm on a few pillows next to you or on the back of a couch. Don't hold your arm over your head for long periods of time. It may cause the muscles of your arm to get tired.
 - If you sleep on your back, rest your arm on 1 or 2 pillows at your side. If you sleep on the opposite side of your surgery, rest your arm on 1 or 2 pillows in front of you.
 - **If the swelling does not decrease after 1 week, call your doctor.**
- Notice when the swelling in your arm gets better or worse, such as in the morning after sleeping, or in the evening after using it all day. Notice what you do with your arm, such as carrying heavy bags, typing, or chopping vegetables. Some people find that using their affected arm helps reduce the swelling, while other people find that it makes the swelling worse. If something you do makes your arm uncomfortable or swollen, take breaks when you do it. You may also try wearing a compression garment during these activities.
- Wear a compression garment or low-stretch lymphedema bandage when you travel in an airplane. Don't use an Ace™ bandage. The compression garment should extend to your hand, even if you usually use one that ends at your wrist. If you're wearing compression garments for the first time, you should test them before your flight.

- Make sure the garment is comfortable enough to wear the entire flight.
- Make sure the garment doesn't cause new swelling in your hand or arm.

Lymphedema bandages are more bulky and difficult to apply than compression garments, but they may be more comfortable for longer flights. Ask your lymphedema therapist to show you how to apply them properly.

Is it safe to resume my prior activities and exercise routines?

We encourage you to keep doing all of the activities that you enjoy. Research has shown that no activity level, occupation, or hobby is related to developing lymphedema. In fact, weight training has been shown to be safe and may help prevent lymphedema from developing.

You should resume activities slowly and gradually. You may choose to modify an activity if you notice that it causes more swelling or discomfort in your arm. Talk with your doctor and lymphedema therapist for help modifying your exercises or activities.

If you have swelling in your arm or hand, wear a compression garment or bandage when:

- Doing resistance exercises
- Doing repetitive activities
- Doing physically demanding chores, such as house cleaning
- Playing sports

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

It's common to feel anger and frustration when you learn that you have lymphedema. Some people feel depressed. If you're 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 people with lymphedema. They can be harder to treat and spread more quickly. Having an infection in your arm, hand, breast, or torso on your affected side can make the lymphedema worse. Call your doctor right away if you have any signs of infection, such as:

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

If you have infections that keep coming back, ask your doctor if you should see an infectious disease specialist.

Not all pain or new sensations are the result of lymphedema. Sometimes, they can be caused by another disorder. Lymphedema can increase your risk for other disorders that cause pain, so it's important to talk with your doctor if you're having pain or new sensations.

Causes of arm pain include:

- Infection
- The swelling itself
- Deep vein thrombosis (DVT), which is a blood clot in a vein deep in the body
- 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 damage)

If you have any questions about lymphedema, talk with your lymphedema therapist. If you are not seeing a lymphedema therapist but would like to, talk with your doctor or nurse.

Resources

National Lymphedema Network

Provides educational materials and community referrals.

www.lymphnet.org

Telephone: 415-908-3681

Hotline: 800-541-3259

American Cancer Society

Provides information about the diagnosis and treatment of lymphedema.

www.cancer.org

800-227-2345

National Cancer Institute

Provides information about the diagnosis and treatment of lymphedema.

www.cancer.gov

1-800-4-CANCER

Step Up, Speak Out

Provides resources and educational materials about lymphedema

www.stepup-speakout.org

If you have any questions, contact a member of your healthcare team directly. If you're a patient at MSK and you need to reach a provider after 5:00 PM, during the weekend, or on a holiday, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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