

Lymphedema

What is lymphedema?

Lymphedema is a condition that happens when a fluid called “lymph” builds up in the tissues of your body instead of flowing normally throughout your body. It is a common side effect (problem) of any cancer treatment that affects the lymphatic system, usually radiation therapy or surgery. Lymphedema can occur in people with bladder cancer, breast cancer, cancers of the head and neck, cancer of the penis, melanoma, ovarian cancer, prostate cancer, and other cancers.

Lymphedema causes swelling and can also cause discomfort and pain. Lymphedema only affects the areas where lymph nodes were removed by surgery or targeted by radiation therapy. It is most common in an arm or leg, but it can also happen in the neck, face, mouth, abdomen, groin, or other parts of the body. Lymphedema may lead to changes in the skin and might keep you from doing your usual activities. These skin changes may increase your risk of serious skin infections.



What causes lymphedema?

Missing or damaged lymph nodes can cause lymphedema. Your lymph system carries fluid with white blood cells all through your body. The cells gather harmful items, such as viruses, and carry it to the lymph nodes, which are small bean-shaped organs that filter out those harmful items.

When your lymph nodes are taken out or damaged by cancer, surgery, radiation therapy, or an infection, they cannot filter the lymph fluid properly and keep it flowing. Fluid might then build up in the tissues where those lymph nodes normally drain.

If you have had a cancer treatment that affected your lymph nodes, it may be helpful to avoid burns, scrapes, cuts, and heavy lifting, which can affect your lymph system. It may also be helpful to avoid extreme temperatures, maintain a healthy weight, and wear loose-fitting clothes around the area where lymph nodes were affected. Talk with your health care team to see if you are at risk for lymphedema.

How is lymphedema diagnosed?

If you notice swelling, heaviness, pain, or skin changes in your arm, leg, neck, or other place, be sure to let your cancer care team know. Your doctor might be able to tell you have lymphedema just by looking at the area. Or they might need to do an examination. For instance, your doctor may measure an affected arm or leg. Your doctor then compares the measurements to learn if the one part of the body is holding more fluid than the other. Swelling may come and go, and early diagnosis and treatment of lymphedema are very important. Some clinics have special tools that can measure size and fluid in the tissues.

How is lymphedema managed and treated?

Lymphedema is treated by trained lymphedema experts, usually physical and occupational therapists. Treatments include a special type of massage to help fluid flow through the area and exercises with a physical therapist or on your own. You might also wear a “compression garment,” a piece of elastic clothing that helps push fluid out of the swollen area. A treatment called “complete decongestive therapy” includes all the steps listed above. Wearing sunscreen, using moisturizer, and avoiding bumps, scrapes, and cuts on the area with lymphedema are important to prevent infection and protect your skin. Other treatments include raising the affected area higher than your heart to let fluid drain. You might also receive a special lymphedema pump or surgery. Researchers are testing other treatments for lymphedema, so you may want to ask your doctor about joining a clinical trial.

Questions to ask the health care team

You might have heard of lymphedema, think you have it, or want to avoid it. Regular communication is important in making informed decisions about your health care. It can be helpful to bring someone along to your appointments to take notes. Here are some questions to ask your health care team.

- Do you need to take out any lymph nodes as part of my treatment? Which ones?
- Does my treatment or type of cancer put me at risk for lymphedema?
- How high do you think the risk is?
- What can I do to lower my risk of developing lymphedema?
- What signs should I look for if I think I may have lymphedema?
- What should I do if I have lymphedema?
- What are the next steps in treating lymphedema?
- How can I find a clinical trial for lymphedema treatment?

Find more information at www.cancer.net/lymphedema and more questions to ask your health care team at www.cancer.net/questions. For a digital list of questions, download Cancer.Net's free mobile app at www.cancer.net/app.

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2318 Mill Road, Suite 800, Alexandria, VA 22314 | Toll Free: 888-651-3038 | Phone: 571-483-1300
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WORDS TO KNOW

Clinical trials:

Research studies that use volunteers to test new medications and other treatments. Clinical trial treatments are safe enough to study, but not yet available to the public.

Lymph:

A fluid that travels through your body collecting germs and materials that can harm you. Lymph is filled with white blood cells, which fight infection. The lymph carries harmful materials to your lymph nodes for filtering.

Lymphatic system:

A system that carries fluid called "lymph" through your body, cleaning and removing germs and other material.

Lymph nodes:

Small organs located in certain areas in your body, including the armpits, groin, and neck. They act like small filters that remove germs and other harmful materials from the lymph.

Node-positive:

Lymph nodes that have cancer in them. If cancer spreads to the lymph nodes, they will probably be removed because cancer can spread from them to other parts of the body.

Radiation therapy:

The use of high-energy x-rays to destroy cancer cells.

Side effects:

Problems that happen during or after treatment. These could be from the cancer or how the treatment affects your body.

Surgery:

Removing tissue from the body by cutting it out.

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