

Lymphedema Program

In the Lymphedema Program at Seattle Children's, we will evaluate your child and develop a treatment plan to address the lymphedema and teach you how to manage it at home.

What is lymphedema?

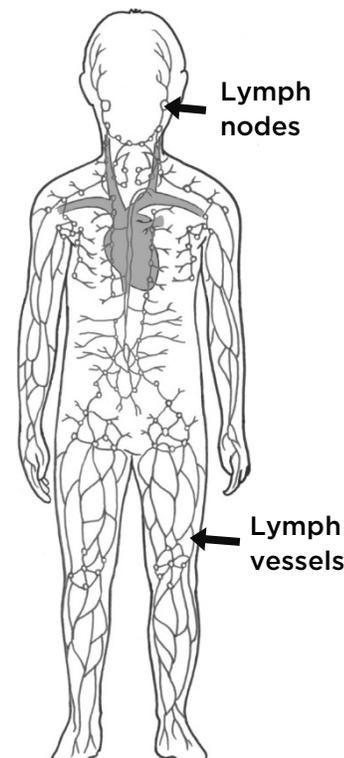
Lymphedema is swelling that happens when thick, protein-rich fluid called lymph builds up in the body. This happens because of a problem in the lymph system.

Usually lymphedema affects an arm or leg, but it can also affect the head, neck and trunk. The area gets larger than normal because of the lymph fluid building up. It may look puffy, and the skin may appear tight.

You may notice that your child's clothes or shoes don't fit well over the swollen part. The area may feel full, heavy or achy to your child. The body part might become harder to move or bend.

Swelling may be worse at the end of the day or after your child has been more active.

Minor swelling in an arm or leg may improve if your child lies down and raises the limb higher than the heart. In most cases, lymphedema will not get better with this step.



What is the lymph system?

- Lymph: A thick, protein-rich fluid that runs through the lymph system. White blood cells (lymphocytes) travel in the lymph, fighting infection and disease. Lymph also carries protein and waste from cells.
- Lymph nodes: Bean-like structures that filter fluid and serve as centers where the body fights disease.
- Lymph vessels: A network of small tubes that connect the lymph nodes.
- Lymph system: A network of small tubes (vessels) and nodes that pick up lymph fluid from all around the body. The fluid moves through these vessels and the lymph nodes into the large veins that return blood to the heart.

What causes lymphedema and who gets it?

Lymphedema occurs when the lymph system can't drain lymph fluid well. Reasons why the lymph system can't drain well:

- There aren't enough lymph vessels or lymph nodes
- The vessels are too big or too small

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To Learn More

- Vascular Anomalies
206-987-4606
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

- The vessels didn't form as they should
- The vessels or nodes were damaged

Lymphedema is not the same as the normal swelling that happens after a common injury, like a sprained ankle. Normal swelling usually goes away for good after a few days or weeks, but lymphedema does not get better on its own.

Primary lymphedema

In primary lymphedema, your child is born without some lymph vessels or nodes. It is also possible the vessels or nodes didn't form normally and don't collect or filter lymph fluid the way they should. Symptoms may be present at birth or may not appear until your child is older. Sometimes symptoms start during a growth spurt in an older child or teen.

Secondary lymphedema

In secondary lymphedema, your child was born with healthy lymph nodes and vessels, but now the lymph fluid doesn't flow the way it should because they were damaged or removed. Causes may include cancer treatment, injury or infection.

Will lymphedema get better or worse?

Lymphedema is a long-lasting (chronic) condition that won't go away. It gets worse if it's not treated. Once lymph collects, it pulls more fluid to that area. Lymphedema can also lead to hardening of the skin and tissue (fibrosis), which makes it harder for lymph fluid to drain.

Swelling and fibrosis keep oxygen and nutrients from getting into the area. This can keep wounds from healing well, and it can increase the risk for infection in the skin (cellulitis) and lymph vessels (lymphangitis).

How is lymphedema treated?

The lymphedema program at Seattle Children's Hospital includes a team of doctors, nurses, and certified lymphedema therapists, occupational therapists and physical therapists with extra training to manage lymphedema. If your child is referred to the program, we will evaluate your child and develop a treatment plan just for them using Complete Decongestive Therapy (CDT).

There are 4 parts to Complete Decongestive Therapy (CDT):

- **Skin care:** Simple steps can help keep your child's skin healthy and prevent infections or give you a chance to notice and treat any infection early. Your child's therapist will teach you and your child how to keep the skin clean, how to take care of minor wounds and which signs might mean the skin is infected.
- **Manual lymph drainage:** This special method of gentle massage can improve the flow of lymph into and through the lymph vessels. Your child's therapist will use this method to drain a swollen area. We'll also teach you and your child how to do this at home.
- **Compression therapy:** Wrapping a swollen limb with short stretch bandages can get lymph to flow out of the limb into the trunk. Your child's therapist will do this and will also teach you and your child to use wrapping at home. Once the swelling goes down, the therapist will measure your child for custom compression garments. Your child wears these special sleeves or stockings to keep pressure on the area and prevent lymph from building up again.

- **Exercise:** Certain actions that move the muscles and skin can stimulate the lymph system. Your child's therapist will create a simple home program that's right for your child to promote movement throughout the day.

Treatment phases

We give you and your child information and training on how to do this therapy at home. It's important to manage your child's lymphedema by providing ongoing and consistent therapy. There are 2 phases of treatment provided at Seattle Children's Hospital.

Phase 1

In phase 1, we may see your child 3 to 5 times a week for 1 to 2-hour treatment and education sessions. This phase depends on the severity of your child's lymphedema and may last 2 to 4 weeks. The goal of this phase is to decrease the lymphedema and train you to complete a complete decongestive therapy with your child at home. It is likely we will measure your child for a custom compression garment at the end of this phase.

Phase 2

Once the lymphedema has decreased and you feel comfortable with how to manage your child's lymphedema at home, your child will be in phase 2 of treatment. During phase 2, we will fit your child with a custom compression garment and see them about 1 time a week for 1 month. Then we will see your child 1 time per month as needed. You need to replace your child's compression garment every 4 to 6 months. To learn more, read our handout "Compression Garments" seattlechildrens.org/pdf/PE1840.pdf.