**Lymphedema Program**

**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 system:** A network of small tubes (vessels) and nodes that pick up lymph fluid from all around the body. These vessels channel the lymph through the lymph nodes and into the large veins that return blood to the heart. White blood cells called lymphocytes travel in the lymph, fighting infection and disease. Lymph also carries protein and waste from cells.
- **Lymph nodes:** Bean-like structures that 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:** A thick, protein-rich fluid that runs though the lymph system.

**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
- 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, your child will be evaluated and a treatment plan will be developed 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

An important part of this treatment also focuses on giving you and your child information and training of how to complete this therapy when you are at home. In order to manage your child’s lymphedema, family members will need to provide ongoing and consistent therapy. There are 2 phases of treatment provided at Seattle Children’s Hospital.

#### Phase 1

In phase 1, your child may be seen 3 to 5 times a week for 1 to 2 hour sessions for treatment and education. 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. Your child will likely be measured 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, your child will be fitted for their custom compression garment and will be seen about 1 time a week for 1 month. Then 1 time per month as needed. Your child's compression garment will need to be replaced every 4 to 6 months. To learn more, read our handout “Compression Garments” www.seattlechildrens.org/pdf/PE1840.pdf.

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Seattle Children’s offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children’s will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

This handout has been reviewed by clinical staff at Seattle Children’s. However, your child’s needs are unique. Before you act or rely upon this information, please talk with your child’s healthcare provider.

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