



Lymphoedema in Children

A Parent and Patient's Guide

What is Lymphoedema?

Lymphoedema results from a failure of the lymphatic system. Consequences are swelling, skin and tissue changes and a risk of infection. It most commonly affects the lower or upper limbs but may also affect midline structures such as the face, neck, trunk, breasts or genitalia.¹

Any child with a known or suspected diagnosis of lymphoedema should be referred to a Specialist Paediatric Lymphoedema Service.²

What is the lymphatic system?

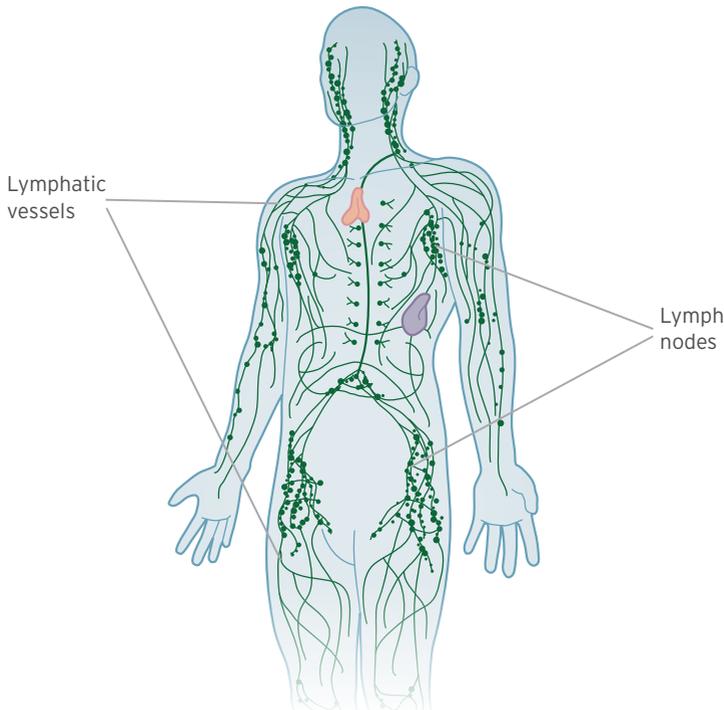
It is important to understand what the lymphatic system is and its function within the body.

The **lymphatic system** is a network of lymph vessels and lymph nodes that rid the body of toxins and waste to help protect it from infection and disease and absorb fat from the intestine.

Lymph is the fluid that circulates throughout the lymphatic system. It contains a variety of substances, including proteins, salts, glucose, fats, water and white blood cells.

Lymph nodes work as filters, trapping viruses and bacteria before they can infect other parts of the body. They contain immune cells that can help fight infection.

Lymphoedema occurs when the lymphatic system cannot collect or transport the lymph fluid, this causes the lymph fluid to build up in the tissues, resulting in swelling and changes in skin appearance and texture.



Causes and Diagnosis of Childhood Lymphoedema

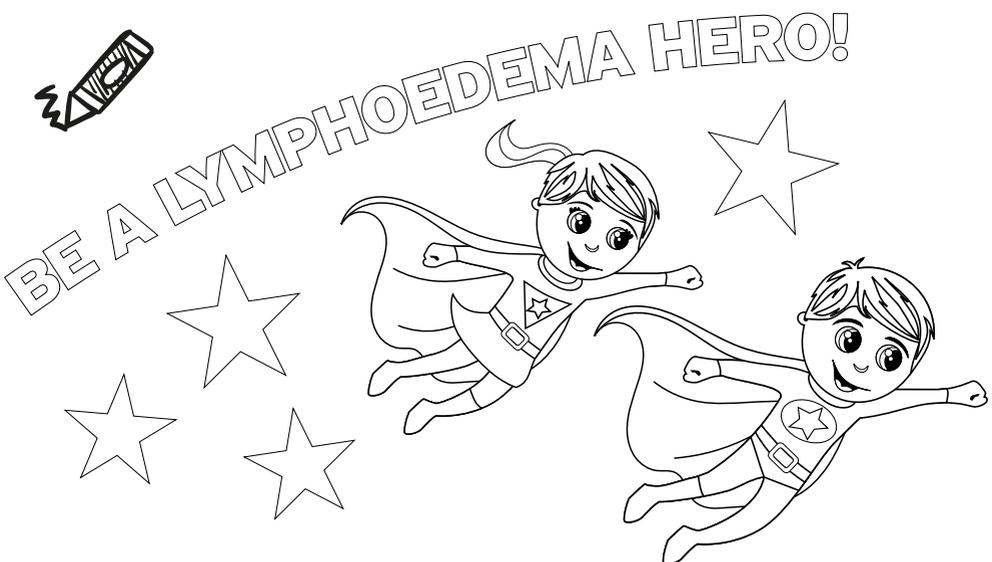


Other causes of swelling should be investigated first and once these have been excluded and lymphoedema is suspected, your child should be referred to a Specialist Paediatric Lymphoedema Service.

There are five main classifications of primary lymphoedema, and there are many known syndromes that have been linked to it e.g. Noonan Syndrome, Prader Willi, Yellow Nail Syndrome, Turner Syndrome.³

1. Congenital onset (e.g. Milroy's disease) - lymphoedema is noticeable at birth or presents before the age of one
2. Disturbed growth / cutaneous manifestations / vascular anomalies (e.g. Klippel-Trenaunay Syndrome, Proteus Syndrome)
3. Systemic / visceral involvement: pre-natal or post-natal onset (e.g. generalised lymphatic dysplasia)
4. Syndromic (e.g. known / unknown syndrome) - refers to a group of abnormalities, one of which may be lymphoedema
5. Late onset (e.g. Meige) - lymphoedema presents after one year of age

All children with lymphoedema should have access to one of the specialist centres for paediatric lymphoedema (e.g. Derby and London) where investigations and genetic screening can be offered to determine the exact cause.²



Treatment and Management

How is lymphoedema managed?

There are two stages in the treatment and management of lymphoedema

- Intensive treatment also known as decongestion
- Long term maintenance and self-management

The level of your child's swelling will determine which stage they will start their treatment.

Intensive treatment

If a lot of lymph fluid has built up in your child's limb or body, treatment will commence at this stage. The aim is to reduce limb volume over a period of approximately two-four weeks, using some of the following techniques.

- Compression bandaging
- Wrap compression systems
- Pneumatic pump compression
- Manual and / or simple lymphatic drainage massage
- Recommended exercises
- Good skin care regime

Intensive treatment is always followed by long-term maintenance.

Long term maintenance and self-management

If symptoms are presented with minimal swelling and / or there is a good limb shape, your child may commence treatment at this stage. The aim is to maintain and optimise the limb shape using some of the following techniques.

- Daytime / night time compression garments
- Wrap compression systems
- Recommended exercises
- Manual and / or simple lymphatic drainage massage
- Good skin care regime

Treatment considerations

- The maturing lymphatic system, growth and development of your child
- The acceptability of the form of treatment to you and your child and effects on quality of life
- The psychosocial impact of having lymphoedema on you and your child

Massage - manual and / or simple lymphatic drainage

Exercise

Corner Stones of Treatment

Compression therapy

Skin care



How Can Diet Help?

A healthy, balanced diet is important for every child's health and development but is equally important for children who suffer from lymphoedema as being over-weight can make the swelling worse.⁴

The lymphatic system plays an important part in the removal of toxins, and harmful organisms from the tissues and fat absorption. If the lymphatic system is compromised, this can have an impact on the body's ability to remove excess fat.⁴

Some types of lymphoedema affect the gut and it may be necessary to follow a specific diet, but this would be recommended by your Specialist Lymphoedema Service.

A healthy low-fat diet can have significant benefits to patients with lymphoedema by helping to limit the intake of toxins and fats that can cause aches, pains and fatty deposits.⁴



What Activities / Exercise Can my Child Take Part in?

Unlike the blood circulatory system which has the heart to pump blood around the body, the lymphatic system is a one-way drainage system. It relies on our movement and the contractions of all our muscles, including deep breathing, to move the lymph fluid along.

The superficial lymphatics are positioned just underneath the skin. When exercising or moving, the muscles contract and relax against the skin and this in turn increases lymphatic activity thereby helping to reduce swelling.⁵

Wearing a compression garment or bandages during exercise and movement provides increased resistance for the muscles to work against and can therefore improve lymphatic flow.

Children should not be limited by their condition and should be encouraged to exercise and join in activities that they enjoy. Remember it is important to:

- Monitor swelling after strenuous activities, any increase in oedema should resolve quickly
- Make sure compression therapy is worn during activities - where possible
- Cuts and scrapes should be cleaned thoroughly and covered to prevent infection

What I Need to Monitor?

As your child has lymphoedema, they will be at greater risk of developing skin infection such as cellulitis. This is because the lymphatics play a big role in the body's immune system.

Nail care is a very important part of management for patients with lymphoedema

Any damage and / or broken skin around the nails, may cause **fungal** or **bacterial** skin infections, which may lead to more serious infections such as cellulitis.

Skin infections around the fingers and toes

Fungal infections are often associated with Athlete's foot. Feet and in between the toes should be dried thoroughly and moisturised, to prevent skin from cracking. This is a key preventative activity and should be done daily.

Bacterial infections that develop around finger or toe nails may be caused as a result of:

- On the fingers: this is commonly caused by a hangnail
- On the foot: it is commonly caused by an ingrown toenail

What to monitor:

Check the nails and skin around the nail bed and between toes daily. Monitor the condition of the skin around the nails as well as the nail itself. If there is an appearance of increased swelling, unusual redness, your child - parent point of view your child is feeling unwell for no apparent reason, this may indicate the presence of an infection and prompt medical treatment is advised.

Dry feet and between the toes well following bathing, swimming or other activities that result in feet getting wet.

Keep toe nails trimmed, nails should be properly trimmed. Often children with lymphoedema will have lifted toes nail like a 'ski jump', keeping these nails trimmed may prevent trauma and damage to the nail bed and surrounding tissues.

Never cut down the side of the nail or into corners and do not cut nails too short.

Shoes

Children should have their feet measured for length and width to get correctly fitting shoes, which should cover the top of the foot. Some children may need specialist shoes and your lymphoedema specialist would be able to advise.

Socks

Socks should not have a tight top band which may restrict lymph flow. Also, socks must allow room at the toes.

Recognising Signs of Infection and Cellulitis

It is important to be aware of the early signs of infection in order to treat promptly. If the signs of infection are observed, then seek medical advice immediately.

Contact your GP straight away if you notice flu-like symptoms or any of the following signs of infection:



Redness or warmth in the limb that's at risk



Painful swelling in a limb that was not swollen before



Pain or tenderness in the limb that's at risk



Red streaks that go up or down from the affected area



High temperature or fever



Vomiting



Headache



Tiredness or fatigue



Rash



Light sensitivity



Confusion



Seizures



Creating a Support Network

Communication

If your child attends nursery or is of school age, it is important to inform the school of your child's condition so that your child can get the support and care that they require to help.²

This may include:

- Preventing avoidable school absence due to their lymphoedema
- Support your child if school absence is necessary
- Treat cuts and scrapes quickly and effectively to prevent infection
- Ensure compression garments are worn throughout the day and that additional time is allowed when changing is required e.g. Physical Education
- Monitor your child's self-esteem
- Help to educate other children about lymphoedema and address any misunderstandings of the condition to help prevent isolation and potential bullying

It is also important to communicate this information to any club, family member or adult that may be looking after your child in your absence e.g. - sleeping over at a friend's house.

Involvement

Your child's teachers and school nurse should be aware of your child's treatment regime and have contact with the lymphoedema service and contact point in the case of emergencies, so the needs of your child can be supported throughout their education.

Collaboration

Collaboration and communication between the lymphoedema service and school may be required as your child transitions through their education, from nursery to primary school and then to secondary school. This will ensure their support is continued in the same manner that they are comfortable and familiar with.



“ TRISTEN IS A REAL ROLE MODEL FOR A LOT OF THESE KIDS ”

“ These kids are seeing that you're not going to be limited by this. ”

Tammy, mum to Tristen with primary lymphoedema

LYMPHCONNECT®: YOUR LYMPHOEDEMA. YOUR LIFE. JOIN TODAY AND BE PART OF THIS EXCITING ONLINE COMMUNITY

Lymphoedema is a unique and chronic condition that can be overwhelming and may be associated with feeling anxious or alone. The good news is that you are NOT alone! Thanks to LymphConnect® you can become part of an online lymphoedema community.

- Connect with others
- Be encouraged by their stories
- Share experiences
- Learn more about chronic swellings
- Get support when needed

Register today and learn more about how Tristen and his mum manage his lymphoedema or email support@lymphconnect.co.uk for more information.

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Word Search

1. Cream
2. Swelling
3. Lymphoedema
4. Compression
5. Sport
6. Exercise
7. Sock
8. Stocking
9. Cuts
10. Infection
11. Lymphatics
12. Genes

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Supporting Your Treatment

Your lymphoedema specialist will recommend appropriate treatment, suitable to your condition. They will always try to accommodate individual needs by working with you, in partnership, to find the best treatment solution.

To achieve the best outcomes and prevent complications and worsening of your child’s condition, it is important that treatment requirements are complied with.

Additional Support

The Lymphoedema Support Network (LSN) and The British Lymphology Society (BLS) websites contain the CLSIG Register of Paediatric Clinics in the UK, which is a directory of lymphoedema services providing treatment of children and young people with lymphoedema.

The links below are some recommended sites that you may find useful:

- The Lymphoedema Support Network (LSN)** - www.lymphoedema.org
- British Lymphology Society (BLS)** - www.thebls.com
- The NHS** - www.nhs.uk/conditions/lymphoedema
- LymphConnect®** - www.lymphconnect.co.uk

References

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