

Patient information from BMJ

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Lymphoedema: what is it?

The lymphatic system is part of the body's defence against infection. But if you have lymphoedema, a build-up of fluid in the lymphatic system causes swelling, usually in the arms or legs.

There is no cure for lymphoedema, but there are treatments that can help to control it. You can use our information to talk with your doctor about the best treatments for you.

For more information, see our leaflet: *Lymphoedema: what treatments are available?*

What is lymphoedema?

The lymphatic system is usually thought of as part of the immune system, because it makes white blood cells, which destroy invading infections.

Glands in the lymphatic system help to prevent infections from spreading around the body by finding and destroying germs in the lymphatic fluid.

You might know that there are lymph glands (also called lymph nodes) in the armpits, neck, and groin. But there are hundreds of them in other places around the body.

The lymphatic system does several other jobs. For example, a clear liquid called **lymph** flows through the lymphatic system, helping to:

- remove fluid from body tissues and return it to the bloodstream
- absorb fats from your digestive system, and
- remove waste products from your body fluids.

Lymphoedema happens when something stops fluid from flowing easily around the lymphatic system. This causes parts of the body, often the arms or legs, to swell (**oedema** means swelling).

This swelling makes people with lymphoedema especially prone to a skin infection called **cellulitis**. Cellulitis can also be a cause of lymphoedema in the first place.

Cellulitis can be treated with **antibiotics**, but it can sometimes be serious. Doctors give advice to people with lymphoedema about how to protect their skin from infection, and how to get treatment quickly when an infection happens.

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There are two types of lymphoedema. These are called **primary** and **secondary** lymphoedema.

Primary lymphoedema

Primary lymphoedema is a genetic condition. That means that it is caused by the genes you were born with. This type of lymphoedema is not caused by something external, like an illness or an injury.

In **boys**, the symptoms of primary lymphoedema usually start when they are babies or very young children. In **girls**, the symptoms are more likely to start in the teenage years. It's rare for primary lymphoedema symptoms to start when someone is an adult.

Secondary lymphoedema

This type of lymphoedema is not genetic. It can be caused by several things. The most common causes are:

- some types of **cancer**, which can damage the lymphatic system
- having **treatment for cancer**. For example, lymph nodes sometimes need to be removed as part of cancer surgery if they are close to a tumour. Surgeons take care to damage the lymphatic system as little as possible. But if a lot of tissue has to be removed it's not always possible to prevent problems
- **skin infections**, such as cellulitis, which can damage the tissue around the lymphatic system
- an infection called **filariasis**, which is caused by tiny parasitic worms that live in the lymphatic system. This infection is spread by mosquitoes and is not common in developed countries
- **physical injuries**. For example, an injury that causes a lot of bruising, such as a traffic accident, can damage some tissues of the lymphatic system.

What are the symptoms?

The main symptom lymphoedema is painless **swelling**, usually in the legs. The swelling can also happen in the arms and, very rarely, in the genitals.

You might also feel **heaviness** and **weakness** in the limbs that are affected.

If your doctor thinks that you might have lymphoedema, he or she will ask you about things that can cause it. For example, your doctor might ask about whether you have ever:

- had cancer treatment
- travelled to an area where filariasis is endemic (widespread), or
- had surgery.

Your doctor might also want to do some **tests**. These might include:

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- a **lymphoscintigram**. In this test, a tiny amount of radioactive liquid is injected under the skin. This helps to build up an image of the lymphatic system, which can help show whether you have lymphoedema
- an ultrasound, MRI, or CT **scan**, which can help to show if you have a problem other than than lymphoedema, and
- a **blood test** for filariasis, if your doctor thinks this is a possibility.

What to expect in the future?

There is no cure for lymphoedema, but there are treatments that can help reduce the swelling and the risk of cellulitis. And, while your doctor will stress how important it is to keep up with your treatments, it can sometimes be hard to stay motivated.

For example, there might be times when you feel on top of things and your symptoms improve; but there will probably also be tough times when you find it hard to stay positive.

Things such as the clothes you need to wear, the way you feel about your appearance, infections, and problems moving your limbs can affect your quality of life and get you down. It can be easy to become depressed and anxious.

So it's important to make the most of what your doctor might call **psychosocial support**. This sounds like a fancy term. But it just means any help that you get with your mental and social well being.

This help can come from professionals, or it can be from friends, family, or **support groups**. For example, in the UK, **lymphoedema.org** provides information and support to people with the condition and their families.

Your doctor will want to check on you at least once or twice a year, depending on how severe your symptoms are, and on whether you have problems with **cellulitis**.

He or she will monitor your progress and give you help and advice on treatments, and how to avoid complications such as infections.

Exercise and maintaining a healthy weight both help with the symptoms of lymphoedema.

Your doctor should explain to you that lymphoedema can sometimes develop into a serious type of cancer called **lymphangiosarcoma**. But this is very rare. It happens to about 1 in every 200 people with lymphoedema.

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