

## Fact sheet: Preventing and treating lymphedema

Your arm feels heavy and prickly or tight, and the rings on your fingers are getting tighter: if you have had breast cancer treatment, these could be the first warning signs of lymphedema (or lymphoedema). Early recognition and action could be critical. Although swelling in the arm might not sound serious, it is unlikely to get better by itself and might keep getting worse if left untreated.

In industrialized countries like Germany, women who have had surgery or received radiation therapy for breast cancer are the people most likely to get this condition. But it can also affect people who have had treatment for other kinds of cancer – and a very small number of people have lymphedema without ever having had cancer. In some countries, certain parasites may enter the lymphatic system and cause lymphedema. Regardless of how it starts, coping with lymphedema can be a difficult process.

People are so concerned about preventing lymphedema that a large number of rules and theories have evolved about what you should or should not do if you have had cancer treatment. It would be easy to get the feeling that everyone who has had cancer treatment has to limit their activities and be constantly vigilant about their arms and legs. That might not be necessary, though. Read on to learn more about your lymphatic system and what researchers have found out about lymphedema, as well as what you can do if you have lymphedema.

## What is lymphedema?

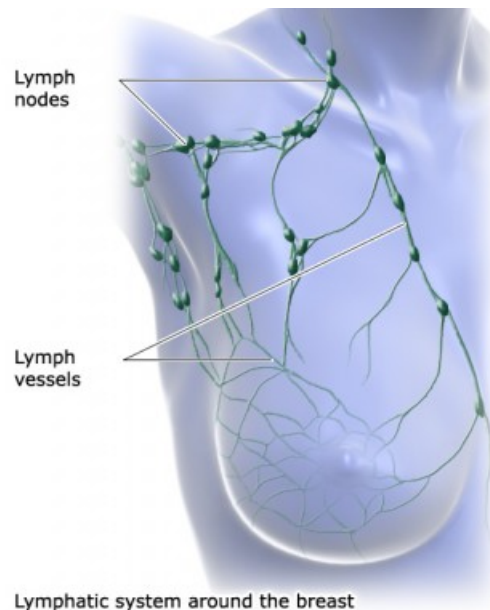
If you have had breast cancer surgery, your surgeon should have discussed lymph nodes and lymph vessels with you, and warned you about the chance that you could develop lymphedema. Lymphedema is swelling, usually of the arm or leg, but it can affect the breast or other parts of the body as well. It is caused by a build-up of fluid called lymph. "Edema" means swelling caused by fluid.

Edema can have other causes, so it is important to see your doctor to make sure that it really is lymphedema. You can read more about the different forms of edema, and their causes and symptoms [here](http://www.informedhealthonline.org/index.458.en.html) (URL: <http://www.informedhealthonline.org/index.458.en.html>).

The lymph or lymphatic system is an important part of our body's system to defend us against infections. This means that if our lymphatic system is not working properly, the problem is not only the swelling and the pain that it causes: it also leaves us more vulnerable to infections.

Lymph travels around the body through a network of vessels in much the same way that blood travels around the body through the blood vessels. Whereas the blood carries nutrients and other substances to our tissues, the lymph vessels drain fluid from the tissues and transport it to the lymph nodes. These small gland-like masses of tissue filter out and destroy bacteria and other harmful substances. The bigger lymph vessels then carry the cleaned fluid back to the vein called the superior vena cava, where it enters the bloodstream. Click [here](http://www.informedhealthonline.org/index.460.en.html) (URL: <http://www.informedhealthonline.org/index.460.en.html>) to see where lymph vessels are found in the body.

Lymphedema happens because the lymph vessels or nodes are damaged in some way. At first it causes swelling as fluid builds up in the tissue and cannot be drained away properly. If it gets worse, infection becomes a risk. Long-term swelling inside the tissues can mean that the fluid goes very deep into the tissue. This can cause fibrosis – a solid thickening of tissue which is very hard to treat.



## What causes lymphedema?

Surgery and radiation can disrupt the lymph vessels. In some cancer surgery, lymph nodes might need to be removed. Vessels and nodes can also be damaged as an unintended adverse effect of treatment. Surgeons try to

avoid procedures that do a lot of damage to the lymphatic system, but this is not always possible.

Temporary lymphedema is common after surgery and does not usually become a chronic problem. It is usually mild, and will go away within a few weeks or months. It does not mean that you are necessarily more likely to develop chronic lymphedema. In fact, it is not possible to predict very accurately who might get lymphedema, or whose lymphedema might get worse.

Lymphedema can develop months or even years after cancer treatment. At least 10 to 20 % of women who have had breast cancer surgery or radiation are likely to get lymphedema to at least some extent, usually within the first 2 years after treatment. Breast cancer surgery can cause lymphedema in the arm, armpit and shoulder area. Surgery in the pelvic area can cause lymphedema in the pelvic or genital area and legs.

Lymphedema caused by cancer treatment or another medical problem is called secondary lymphedema. In some parts of the world, a disease called lymphatic filariasis may cause secondary lymphedema. Filariasis is caused by a parasite (a worm) that gets into the lymphatic system and blocks it. Lymphatic filariasis occurs in a lot of tropical and subtropical areas such as Africa, India, Southeast Asia, South America and the Caribbean.

Primary lymphedema – which has no obvious cause – is far less common than secondary lymphedema. Here the lymphatic system is not able to function properly due to genetic reasons (it runs in families). There are different kinds of primary lymphedema. One of these, called Type I hereditary lymphedema (or Nonne-Milroy syndrome), is often already discovered at birth or in the first 2 years of life. It usually affects both legs. Type II hereditary lymphedema (Meige syndrome) typically arises during puberty. It often affects the arms and legs, and is frequently associated with other abnormalities.

### **What are the symptoms and stages of lymphedema?**

At first lymphedema might not be very noticeable. These are common first signs:

- A full or heavy feeling in the arm, leg or genital area.
- A tight or warm feeling in the skin of the arm, leg or genital area.
- Less movement or flexibility in a hand, wrist or ankle.
- Clothing or jewelry starts to feel tight and uncomfortable.

- The arm or leg starts to look swollen.

Lymphedema develops in stages. At first, the swelling feels soft when you touch it. If you rest your arm or leg or keep it elevated, then the swelling might go down. When you press the swelling, it leaves a dent. Other people may not really notice the swelling: it could just be an extra centimeter or so around your arm.

If the swelling has been there for a while, the area (including the skin) will start to feel firm or hard. When you press it, it does not leave a dent and elevating the limb does not help reduce the swelling.

If it keeps getting worse, the swelling will become very obvious and could be very painful. The area could be numb and movement can get more difficult. You can see changes in the skin, like patches of thick skin and blisters. You could be more prone to infections and inflammations at this stage.

### **How is it diagnosed?**

Especially if you have had cancer treatment, it can be very simple for a doctor to diagnose whether lymphedema is the cause of the swelling. The simplest way is to measure the circumference of your arm or leg.

Your doctor may want to do some tests with devices such as ultrasound machines, which use sound waves to check whether there is a build-up of fluid anywhere in your blood and lymph vessels. A variety of other imaging techniques can sometimes be used, but there is no particular test that has been proven to be the best way to diagnose lymphedema.

### **What can I do to prevent lymphedema after cancer treatment?**

There are long lists of advice about what to do and what not to do to prevent lymphedema if you have had cancer treatment. A lot of these ideas have become standard recommendations, particularly for people who have had breast cancer surgery. These long lists of "do"s and "don't"s developed because of a few basic goals:

- trying to minimize the production of lymph so there is less fluid for the lymphatic system to drain,

- trying to minimize blockage of lymph flow, and
- trying to avoid the risk of infection by avoiding injuries (including small scratches and sunburn).

It all seems quite logical. For example: people often warn against exposing yourself to heat or doing vigorous exercise, because these increase blood flow - and increased blood flow increases lymph production. Other common advice includes not wearing close-fitting clothing because it might block lymph flow. However, there is generally not much real proof that these things can prevent lymphedema, or that not following this advice really puts you at higher risk of getting lymphedema.

Some of this advice could even be counterproductive. For example, some people become very nervous about exercising. Avoiding exercise is not good for your general health – it might even help to reduce lymphedema. In addition, some research shows that exercises for improving arm mobility within the first weeks following breast cancer surgery can improve early arm mobility. Some women were then better able to lift their arms over their head, for example. There is no specific form of exercise, though, that has been proven to prevent lymphedema.

Of course, it is only sensible to stop doing things that you think are causing swelling. Some things are easy to incorporate into your life, such as getting your blood pressure measured on the arm not affected by lymphedema. Avoiding injuries is a good idea for everyone. But having had cancer treatment does not mean that you are now very fragile and have to worry a great deal about trying to do everything you can to prevent lymphedema.

The most important thing might be acting early if you think you have signs of lymphedema: this might reduce your chances of ever developing very severe lymphedema. The longer you have the condition, the harder it is to treat. So early recognition and treatment could be very important.

## What are the treatment options for lymphedema?

There is no proven method that is going to work for everyone. Lymphedema treatment often has several components:

- Compression therapy: This is the best studied treatment. It involves the use of bandages to wrap around the arm

or leg, or special pressure garments or sleeves. The pressure of these garments is adjustable. They aim to help by putting some pressure on the lymph vessels to help them drain fluid away. You need to wear them all through the day, and sometimes at night as well. This is a long-term treatment.

- Lymphatic drainage: That is a special type of gentle massage that aims to help drain the fluid out of the tissues. There are therapists who are specially trained to do this massage. There is no guarantee that it will work, especially without compression therapy.
- Exercises and physiotherapy: These will be tailored to you and your needs by a physiotherapist, who will also monitor you to see how you are reacting to the exercises.
- Skin care: Lymphedema will affect your skin too, so taking care of your skin with moisturizers is an important routine. Your doctor, nurse, physiotherapist or lymphatic drainage therapist will help you with this.

There are also a variety of other treatments, like compression pumps, laser therapy and surgery. Although these might be able to help some people in certain situations, they have not been proven to be generally helpful for lymphedema. You can read more about the research into lymphedema treatment after breast cancer treatment [here](http://www.informedhealthonline.org/index.461.en.html) (URL: <http://www.informedhealthonline.org/index.461.en.html>).

## What can I do myself?

Your doctor or therapist has probably shown you some exercises and perhaps some massage techniques. There is not one particular form of exercise that has been definitely proven to help with lymphedema. As long as you do not notice that the swelling gets worse after a particular exercise or activity, it should be fine to keep doing it. Even progressive resistance training with weights has been shown to help people feel better after breast cancer treatment.

Combining exercise with social activities can help physically and emotionally. Some sporting and recreational activities – like dragon boat racing teams – have been developed specifically for people who have had cancer.

Moisturizers to take care of your skin are important. Some people like to use special moisturizers with aromatherapy

ingredients (scents that are thought to have some ability to heal). Although there are no aromatherapy ingredients or oils that have been proven to help with lymphedema, some people find that using these treatments really makes them feel better.

Some people find that their symptoms get worse if they eat or drink certain things – alcohol or very salty food, for example. There is some evidence that losing weight might help reduce lymphedema in people who are very overweight.

If you have had cancer and you are going to fly, you need to consider the possibility of deep vein thrombosis more than other people do. Having had cancer puts you at a somewhat higher risk, so knowing the signs and using compression stockings or bandages could be very worthwhile. You can read more about this here (URL: <http://www.informedhealthonline.org/index.306.en.html>).

## How do others cope with lymphedema?

For most people, lymphedema will be mild and easy to manage. It might have very little impact on daily life. Even a small amount of swelling, though, can have a negative effect on how the person feels about their body and the way they look. If the lymphedema is mild, other people may not even notice the swelling. If your lymphedema was caused by cancer treatment, it can make it hard to feel you have recovered and that the cancer is behind you.

If lymphedema gets severe, it can be hard to do some things for yourself, which is difficult to adjust to. If you really hate the way your swollen limb looks and, for example, need help getting dressed, that can make your negative feelings even stronger. It is very common to feel embarrassed about how the affected arm or leg looks if the swelling is very bad. It can help to realize that other people probably do not notice it as much as you do.

Do not let the embarrassment keep you at home and away from other people. If your lymphedema is really noticeable to others, it might help if you have rehearsed simple ways of explaining it to people. Your doctor, lymphatic drainage therapist or someone from a self-help group will have helped people through this often, so you could try talking to them to come up with ideas about how to cope. Anger, resentment, embarrassment, fear – all these feelings will be familiar to other people who have struggled with severe lymphedema.

If you are getting depressed, talking to your doctor or a counselor can be very important. People who have recovered from cancer usually return to a good or even better quality of life after a while. If this is not happening for you, you might need help. Many people find a lot of personal support and understanding for what they are going through in cancer self-help groups. Talking with other people who are coping with the same problems might help ease the feeling of being alone and isolated. Getting enough physical and mental help for your lymphedema can help you get back to enjoying your life more again.

More on this topic here (URL: <http://www.gesundheitsinformation.de/lymphoedema.556.56.en.f>).

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## Glossary

### bacteria

Bacteria are micro-organisms that, unlike viruses, can exist on their own. Viruses, on the other hand, can only exist inside a living cell. Most bacteria are not harmful to people, and some are actually beneficial. Bowel bacteria support bowel health. However if they get into the urinary system, they can cause an infection there. Doctors prescribe antibiotics for illnesses where bacteria need to be stopped or killed off. Immunisation is also possible against some bacterial infections, such as diphtheria, tetanus or whooping cough.

### evidence

Evidence is what we call scientific proof from well-conducted, good-quality scientific trials that have been carefully designed to answer specific questions. Depending on the types of questions, different scientific research methods (types of study) are most appropriate to find reliable answers to these questions. Randomized controlled trials (RCTs), for example, are the best way to get reliable evidence on the effectiveness of medical treatments (interventions). This type of study, however, is not the best form of evidence for all possible questions, and does not provide the best answers to all kinds of questions, either. Epidemiological studies, for example, are very suitable for establishing well-founded proof for the spreading of a disease in the population.

### physiotherapist

Physiotherapy is a recognized health-care profession, which in Germany does not require an education on university level such as medical studies. Physiotherapists have completed a three-year training including basic medical knowledge. They are not allowed to make a diagnosis, however, but apply different kinds of therapy on the basis of a doctor's diagnosis or instructions. Physiotherapists mainly use so-called physical techniques such as therapeutic exercises, massage therapy, ultrasound or light therapy.

### infection

In medicine, we speak of an infection when a person has caught a germ (an infectious agent). This germ can be a bacterium, a virus, a fungus or a worm. The germ multiplies and then either spreads throughout the body or

only attacks one particular organ. As long as there are no signs of a disease, this is called an asymptomatic infection. When the body shows a reaction to the germ in the form of symptoms, this is called a symptomatic infection (an infectious disease). The period between the moment the germs enter the body and the moment the first symptoms of the disease appear, is called the incubation period. It may last a few hours or days, or even many years. An infection does not necessarily have to lead to the onset of a disease.

### ultrasound

An ultrasound examination (sonography) is used to visualize the interior parts of the body. In this procedure, the "echoes" of acoustic waves with a frequency above the audible range of human hearing can be turned into images. A special machine sends these waves into the body part to be examined. Depending on the type of tissue, the waves are reflected strongly (e.g. body cavities filled with fluid), weakly, or not at all (e.g. bone tissue). The ultrasound machine turns the echo into an image of the body region examined on a fluorescent screen. Ultrasound examinations are typically done in pregnancy diagnostics, diagnosis of abdominal diseases like gall and kidney problems, or examinations of the thyroid gland and the vessels.

### lymphedema

Lymphedema (from the Latin word *lympha*, meaning: "clear water" and *edema*, Greek for "swelling") is swelling, typically of an arm or leg, because lymph fluid is building up. A breast or another part of the body may be affected as well. Lymph is a clear fluid that circulates through the entire body and plays a role in our immune system, among other things. Lymphedema results when the flow of lymph is affected by damage to the lymph vessels or lymph nodes and the fluid starts to build up in the tissue.

## Sources

IQWiG health information is based on research in the international literature. We identify the most scientifically reliable knowledge currently available, particularly so-called "systematic reviews". These summarize and analyze the results of scientific research on the benefits and harms of treatments and other health care interventions. You can read more about systematic reviews and why these can provide the most trustworthy evidence about the state of knowledge here (URL: <http://www.informedhealthonline.org/index.61.en.html>) . The authors of the major systematic reviews on which our information is based are always approached to help us ensure the medical and scientific accuracy of our products.

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Our information is based primarily on systematic reviews of the effects of health care. Systematic reviews are necessary to gain an objective picture of health care. In order to do this, a clear question is formulated. Researchers then find all the relevant studies that could answer this question. They then evaluate those studies.

You can find a list of the evidence and other scientific literature on which this information is based at **[www.informedhealthonline.org](http://www.informedhealthonline.org)**

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