



➔ **LYMPHOEDEMA** FACTSHEET

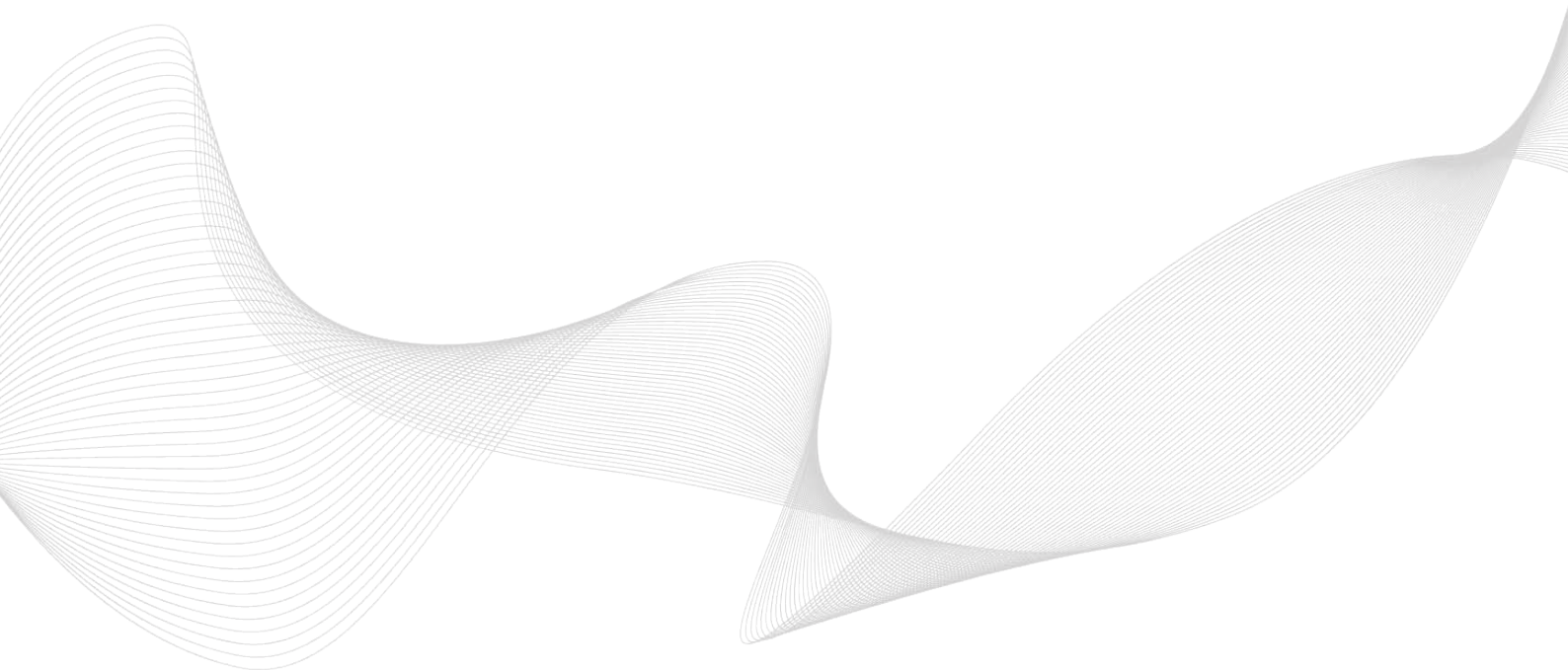
Lymphoedema  
in gynaecological cancers





# What is lymphoedema?

*Sometimes there is a build-up or swelling in the fatty tissues just under your skin caused by trapped lymph fluid. This occurs when the normal flow of lymphatic fluid in the body is disrupted. Abnormal lymph fluid accumulation is called lymphoedema and it can appear in different places in your body, including the legs, genital area, arms, neck, or abdomen, depending which lymph vessels/nodes are damaged.*



## ➔ How does the lymphatic system work?

The lymphatic system is a well-defined entity in the human body that is part of the immune system. It consists of a network of vessels, tissues, and organs, such as the tonsils, spleen, and thymus. Its primary function is to transport lymphatic fluid, called lymph, throughout the body.

The body's cells receive oxygen and nutrients through tissue from fluid seeping from the blood vessels. The lymphatic vessels remove waste, toxins, bacteria, viruses, and other undesirable fluids from tissues, cells, and organs, as a way to fight infections.

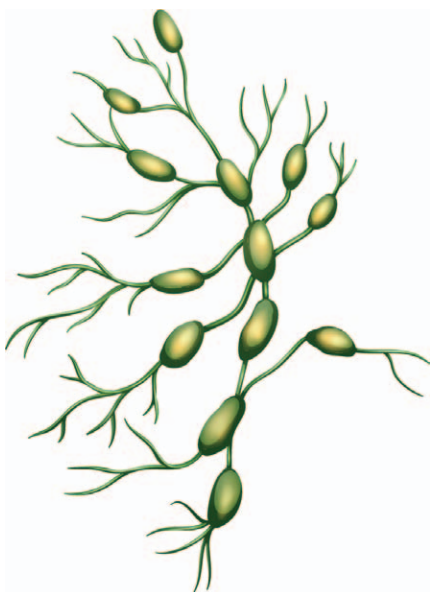
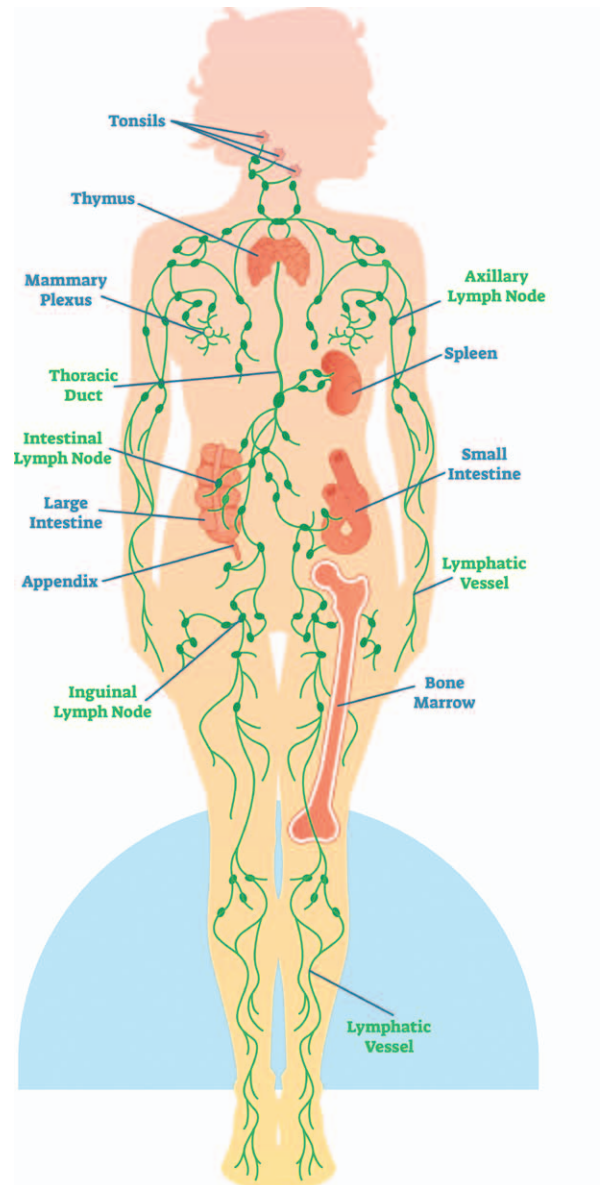
Lymph fluid also absorbs protein and fat from the small intestine after eating.

Lymph moves through the lymph system and collects near the neck, then flows into one of two large ducts.

These large ducts empty into veins under the collarbones, which carry lymph to the heart, where it is returned to the bloodstream.

The body's muscles support lymph circulation; there is no central pump for this process, like the heart for blood.

A lymph node is between 0.5–2cm in size and is shaped a bit like a bean. There are hundreds of lymph nodes in the body—especially in the armpits, groin, and neck, and also around the intestines and in the chest and abdominal cavities.



Lymph nodes act as a sort of guard post (also called a sentinel) that filters and purifies the lymph fluid from bacteria, waste, and cancer cells as well as develops defence cells to help fight infections.

In the case of an infection or the spread of cancer, the nearest lymph nodes may become enlarged.

A damaged or weakened lymphatic system can cause lymph to build up and form a swelling (an oedema).

## ➔ There are two types of lymphoedema

- **PRIMARY**: congenital damage of the lymphatics (rare)
- **SECONDARY**: acquired lymphatic damage (frequent)

## ➔ What are the general causes and risk factors of Secondary Lymphoedema?

**Lymphoedema** is not only caused by cancer or cancer treatment. It may also be caused by increased lymph production, due to renal, heart, or venous failure, or because of reduced flow, as in the case of lymphatic obstruction. A combination of different causes is also frequent.

**Personal risk factors** for developing lymphoedema may also increase the possibility of lymphoedema after lymphadenectomy (surgical removal of lymph nodes):

- Age
- Obesity or impaired nutritional status
- Family history & genetic syndromes
- Affected veins (already existing damage of the veins like thrombophlebitis, chronic venous insufficiency, post-thrombotic syndrome, and deep venous thrombosis)
- Prolonged immobility
- Dermatitis (inflamed skin)
- Advanced cancer
- External compression

### **Therapy-related factors:**

- Surgery with or without removal of lymph nodes
- Radiotherapy
- Surgical site infections
- Orthopaedic surgery

## ➔ Lymphoedema in gynaecological cancers

Lymphoedema is one of the most frequent side effects seen in gynaecological cancers.

During surgery, lymph nodes are often removed, either because they are cancerous, or in order to stage potential spread of the cancer. This can obstruct lymphatic drainage. Cancer treatment, like radiotherapy, can also damage the lymph nodes.

The prevalence of lymphoedema in gynaecological cancers varies from 5–70%. This variation is related to the number and site of lymph nodes removed, type of surgery, and postoperative complications.

In 2019, ENGAGe conducted a survey of all its member groups on the topic of Gynaecological Cancer and Lymphoedema.

From the 278 respondents, 74% had lymph nodes that were surgically removed. The number of nodes removed per patient varied from four to 100.

**In all, 183 respondents (about 65%) reported having lymphoedema at different stages:**

Stage 0	23,5 %
Stage 1	37,7 %
Stage 2	20,8 %
Stage 3	6,0 %

## ➔ Lymphoedema sign and symptoms

Lymphoedema develops individually and can occur right after surgery or after several years. It might affect both legs, but to varying degrees and in different areas. It can also occur in the genital area or the abdomen. The way symptoms develop and appear differs.

### Typical symptoms:

- Swelling, slight to severe, which can make clothes or shoes uncomfortable, particularly in these areas:
  - Whole leg
  - Part of the leg
  - Toes
  - Groin and genitals
  - Abdomen
- Heaviness in the limbs
- Pain or discomfort
- Movement of the affected limb becomes difficult or restricted
- Skin problems, including:
  - tingling
  - infections, particularly recurring infections
  - thickening or roughening of the skin
  - blisters
  - growths
- Extreme tiredness

## Lymphoedema has four stages.

It does not always progress from an early stage to the later stages. However, if it does, it may worsen very slowly. Even though the damaged lymphatic system may never repair fully, it is possible that a patient at stage 0 may never reach stage 1.

### Stage 0: Latent stage

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Lymphatic drainage is damaged due to lymph node removal and/or radiation treatment but there is no noticeable swelling.

This stage may exist for a long time.

### Stage 1: Spontaneously reversible

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The swelling is present, and when a finger is pressed on the surface a pit forms.

The swelling subsides with limb elevation.

### Stage 2a: Spontaneously irreversible

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The swelling pits when pressed by a fingertip but is rarely reduced by limb elevation. It can be reversed with different treatments.



### Stage 2b:

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In the absence of treatment, the tissues become denser and thicker. The swelling doesn't pit anymore due to excess of subcutaneous fat and fibrosis.

The process can only be partially reversed by treatment.



## Stage 3: Lymphostatic Elephantiasis

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The swelling doesn't go away; the skin fibrosis is permanent. Skin changes and thickens. Deposition of fat, warty overgrowths, and lymphorrhea may develop.

It is important to identify the stage, since different therapeutic strategies are available at different stages with different rates of success.

### ➔ Why is lymphoedema usually diagnosed at later stages?

**There are several reasons for late-stage diagnosis:**

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- Lymphoedema is considered a late side effect of cancer treatment
- Detection is difficult in the early stages
- Some health care providers are still very under-educated about the lymphatic system in general and, specifically, about the problem of lymphedema and especially how to treat it
- Health care providers don't have the tools to prevent it or efficient ways to treat it
- Patients are not informed and they ask for help at a later stage
- Co-morbidities (personal risk factors) may act as confounding factors
- Clear diagnostic criteria have not been developed yet

### ➔ How to detect lymphoedema?

There is no golden standard of lymphoedema detection. A lot of clinicians differ in the method and definition.

Patients usually complain of a swollen leg, with intermittent pain, and a feeling of heaviness. These are typical symptoms.

**There are several different methods to recognize lymphoedema.**

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- Measurement and comparison of the limb's circumference is a simple tool, with a cut-off value of 3 cm variance between the limbs as an indicator for a significant difference.
- CT scan or MRI may be used, but these methods are not ideal for following up a patient at risk of lymphoedema due to high costs and the related radiation risk.
- Recently, a technique measuring tissue resistance by electrical energy, called bioimpedance spectroscopy, has been used. It carries no risks and measures lymphedema most precisely.

## ➔ How to prevent or decrease incidence of lymphoedema?

### LYMPHOEDEMA CANNOT BE PREVENTED. BUT IT CAN BE TREATED.

Early detection and management are essential in limiting its effects.

Do not blame yourself if you develop lymphoedema.

➔ **Surgeons can perform** specific procedures to decrease the risk of lymphoedema. The most important one is the use of sentinel lymph node detection (analysis of the first lymph node draining the tumour), which enables them to decrease the number of lymph nodes that need to be removed while offering higher efficacy in terms of detection.

They should also be very careful when handling the lymph nodes during lymph node removal in order not to damage the remaining ones.

➔ **Patients should:**

- Take care of the skin. Keep it moisturized.
- Carefully treat every small injury of the skin. Clean it right away and apply antibacterial ointment and a bandage. Don't get needle sticks.
- Carefully trim and take care of your toenails
- Avoid overheating your body, such as in a warm bath or sauna
- Exercise is the best way to help your muscles move lymph fluid
- Swim regularly to help the flow of lymph out of the limbs—it is a natural massage
- Use compression stockings during the day when you expect to stand or sit for a longer time, or if you travel
- Visit a health care provider to discuss the possible risk of lymphoedema if you feel heaviness or regular pain in your limb or it is swollen.
- Maintain a healthy body weight



## LYMPHOEDEMA IN YOUR EVERYDAY LIFE

*Lymphoedema not only causes physical problems but can also affect a woman's appearance as well as her psychological well-being.*

*Everyday life can become difficult—to unbearable. It robs the sense of joy in life. It is incredibly time-consuming and expensive on a daily basis. It is difficult to walk, to sit, and even to wear shoes or to do simple, everyday things.*

*Heaviness, pain, numbness, and a tingling sensation is often present.*

*Women feel less free and not feminine enough; it affects all aspects of their life.*

*At a later stage, the patient may become functionally disabled due to continuing infections and severe pain; wounds can develop that are extremely difficult to heal.*

*A feeling of shame can appear that may even lead to depression.*

### ➔ How can lymphoedema be treated?

The patient should be thoroughly examined before treatment.

It is very important to discover whether the development of lymphoedema is due to lymph node removal (benign) or due to metastasis (cancer spread) in the lymph node (malignant).

The patient's condition should be monitored closely, as even the medication taken may aggravate the lymphoedema.

The treatment depends on the severity and extent of the condition. The aim is to prevent and control the progression of the oedema and to keep it at the lowest possible stage since there is no cure.

The best thing is to be aware and start taking care of this late side effect even before there are visible signs.

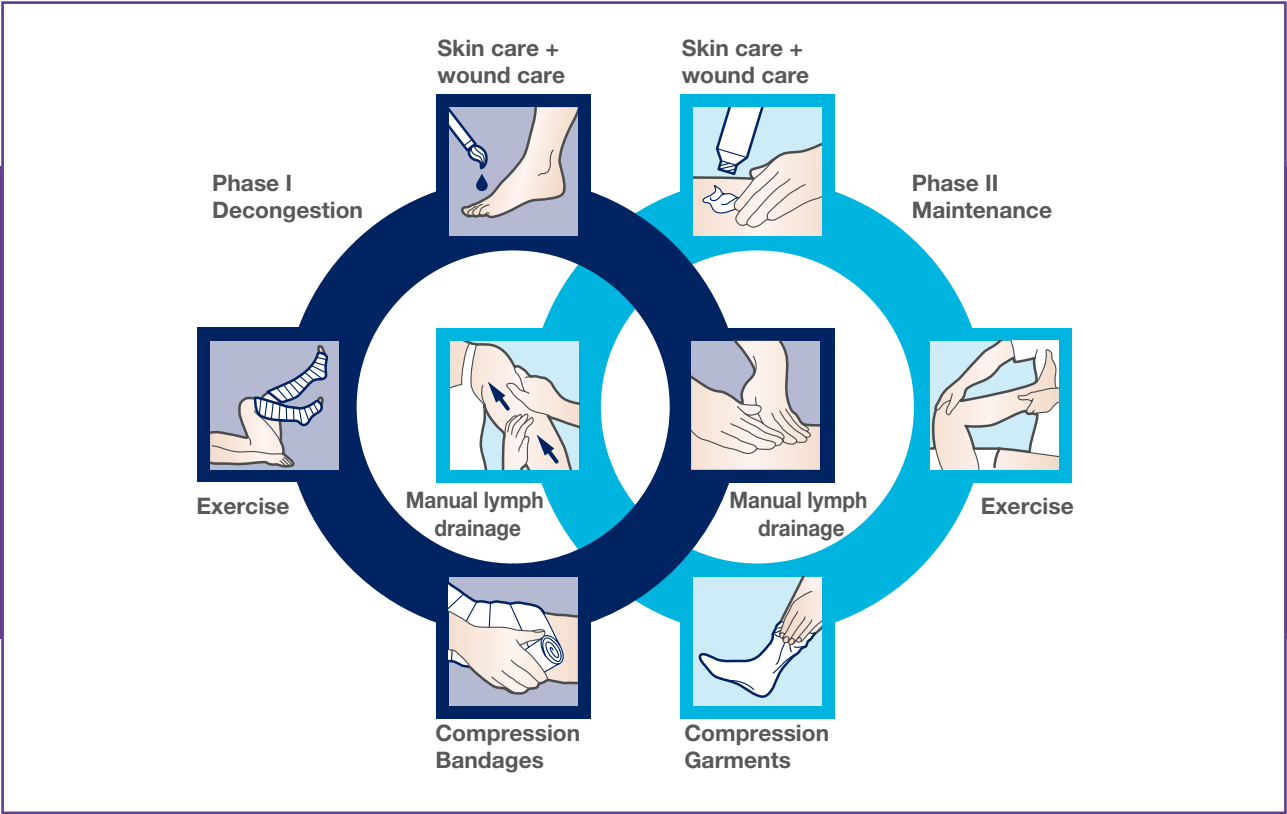
- *If you had removal of lymph nodes during surgery and/or radiotherapy, you are at stage 0.*
- *The lymphoedema may never proceed to stage 1.*
- *Ask your doctor how you can help yourself before you see the first signs developing.*
- *Do not wait for the swelling to appear in order to seek help!*
- *Act now!*
- *Prompt management may decrease the risk of lymphoedema worsening.*
- *Take care of your skin, exercise, and watch your diet.*



The most common treatment is called **complete physiotherapeutic lymphoedema** treatment or **complete decongestive therapy** and it requires lifelong compression therapy. As a rule, the treatment consists of physiotherapy, multilayer bandaging, compression stockings or wraps, exercise, and skincare.

**Other therapies include:**

- Drug therapy
- Compression device
- Plastic surgery



**Compression therapy is for patients in stage 1, 2a, and 2b and consists of two phases:**

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#### **Phase 1 or “Decongestion phase”: professional treatment**

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The purpose of this phase is to support muscles and encourage them to remove mobile oedema fluid from the lymphoedema area and return it back to circulation. This way, the swelling of the affected area is decreased to normal (or as close to normal as possible) while maintaining healthy skin.

This treatment is supplied at an outpatient clinic/hospital and the treatment consists of skincare, massage, bandaging, compression, and exercise. The treatment is performed by specially trained therapists.

The lymphoedema therapist can also help with deep breathing techniques, relaxation, diet, and other ways to improve your everyday life.

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#### **Phase 2 or “Maintenance phase”: treatment by the patient**

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In this phase, patients strive to maintain their improved condition, by continuing to follow the advice of the therapist, using compression stockings, exercising, etc., in order to prevent the swelling from reappearing. Regular visits to the treatment centre may be needed.

It is uncertain how effective lymphatic massage (manual lymph drainage) is in addition to compression therapy.

Recent studies show no or only a minimal effect of a 1–2 hour massage. As the effect is minimal and the treatment is time-consuming, it is doubtful whether manual lymph drainage should be included in the treatment.



## Who should I contact if I see the warning signs?



Treatment specialists can come from different backgrounds, and which one you see depends on what treatment type you have decided to follow.



### **A treatment specialist can be a:**

- Physiotherapist
- Oncologist
- Plastic surgeon
- Vascular Surgeon
- Angiologist (circulatory system doctor)
- Dermatologist

But not all of these are experts on lymphoedema. Make sure that your health care provider specialises in lymphoedema. Check if the hospital near you has a specified treatment team that works with lymphoedema.



### **Additional health care professionals may be:**

- Orthopaedic doctor
- Internist
- Psychotherapist
- Orthopaedic shoemaker
- Social worker
- Dietician

## ➔ Surgical therapy for lymphoedema

Surgical therapy for lymphoedema has greatly advanced from traditional excising approaches, which includes liposuction for late-stage treatment and is done merely to comfort the patient by removing fat—though it doesn't improve lymphatic drainage in the limb.

Different procedures are now available, depending on the stage of the disease and the personal risk factors of the patient. These include the modern microsurgical lymphatic bypass and lymph node transfer.

The best results are achieved in the early stages, and so can decrease the need for physical therapies or a compression garment.

In the early stages (1 and early 2), the microsurgical lymphatic bypass creates connections between still-functional lymphatic vessels in order to return lymphatic fluid to circulation.

Microsurgery can improve the lymphatic drainage function, decrease swelling and heaviness, and delay the progression of the disease.

It can be an outpatient procedure with a very small incision and very little blood loss.

At later stages, (2 and early 3), more lymphatic vessels are damaged but, if there is no severe change on the soft tissues, healthy and functional lymph nodes can be transferred to the affected area in order to rewire the lymphatic system and to reduce swelling. The donor site for the lymph node flap can be tissue from the lateral thorax, the neck, or the intra-abdominal fat. Each lymph node flap is harvested with its nutrient artery and vein and then they are transferred and connected to the artery and vein of the affected limb in order to stimulate lymph flow once again.

Note that these procedures are not available everywhere and in many places are still considered experimental.



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**Contact information of ENGAGE**

**Webpage:** <https://engage.esgo.org/>

**Email:** [engage@esgo.org](mailto:engage@esgo.org)

**Facebook:** <https://www.facebook.com/groups/155472521534076/about/>

**ENGAGE recommends contacting your local patient association!**

