

# **LYMPHEDEMA**

This leaflet discusses lymphedema, a condition that might develop as result of surgery or radiotherapy.

Ask your doctor if you are at risk of developing the condition during your treatment.

THE RECOMMENDATIONS IN THIS LEAFLET SHOULD NEVER REPLACE THOSE OF THE DOCTOR/ONCOLOGIST WHO CLOSELY FOLLOWS YOUR CASE.

## To know

## What is lymphedema?

Lymphedema is a secondary effect of some breast cancer treatments, or caused by the disease itself. It is characterized by an abnormal swelling of the arm and hand, and sometimes, also the breast and chest wall.

The swelling results from a buildup of lymph that is not being drained properly. It appears when several lymphatic vessels/nodes are damaged/removed, e.g. by surgery or radiotherapy, leading to overload of the remaining ones. The resulting blockage causes swelling, discomfort, and, if not treated, even tissue damage.

Fortunately, the increasing use of conservative surgery (where as little as possible of the breast is removed) has reduced the number of patients developing the problem.

## What is the lymphatic system?

The lymphatic system is a whole-body network of lymph nodes and vessels that are vital for our protection against disease.

The lymphatic vessels collect fluid (containing toxins, microorganisms and waste) discharged by cells from organs and tissues, to filter and cleanse in the lymph nodes (which have cells of the immune system), and then return to the blood.

However, by moving fluids from tissues/organs, such as the breasts, into the blood, the lymphatic system acts as a door to cancer cells reach and invade other organs. To avoid this during breast cancer surgery, doctors not only remove the tumor but also the armpit (axillary) lymph nodes and vessels to stop the disease from spreading.

A reduction in lymph vessels and nodes in a part of the body, unless the ones remaining are enough to cope with the lymph flow, will cause swelling and possible lymphedema. Radiotherapy to the lymph nodes can have the same effect.

## Who is at risk of lymphedema?

It is not possible to predict who will develop lymphedema, at least for now, but some people seem to be at higher risk.

#### You are more likely to develop lymphedema if:

- × You had a large number of lymph nodes removed during surgery.
- \* After surgery, you had radiotherapy in the axillary lymph nodes area.
- × You had an infection in the arm or chest from the side you received treatment.

#### Other risk factors:

- \* Recurrent breast cancer that blocks lymphatic circulation.
- × Obesity or weight gain.

# How do I know if I have lymphedema?

A swelling that arises soon after surgery is normal and will disappear over time. If you have radiotherapy, this swelling may even last longer than normal. They are not signs of lymphedema, or a sign that the problem will develop.



## Possible signs of lymphedema:

#### After surgery

If there is a swelling (in the arm, hand, breast, or chest wall) but also one or more of the following symptoms:

- A feeling of heaviness or pain on the operated side.
- The skin of your arm, hand or breast feels stretched
- It feels like your arm gets tired faster than usual

# Possible signs of lymphedema 4 to 6 weeks after surgery

There is a swelling plus:

- The previous symptoms.
- A red area on the skin.
- A recent pain or discomfort on the arm.
- Less movement or flexibility on the joints from the shoulder, hand or wrist.
- Difficulty putting coats and sweaters with sleeves.
- A ring, watch, bracelet or bra that is tighter without having gained weight.

# It is common for lymphedema to first appear associated with a:

- × Injury.
- Infection.
- × A burn.
- × Intense activity.
- × Significant weight gain.
- Air travel (due to changes in pressure).

Although they do not cause lymphedema, these situations can act as the last straw to make them visible

# Contact your doctor:

It is important that you tell your doctor about any unexpected swelling, even if it disappears later, or any possible signs of infection.

Infections in an area affected by lymphedema can progress rapidly, turning into a serious condition fast.

# Prevention

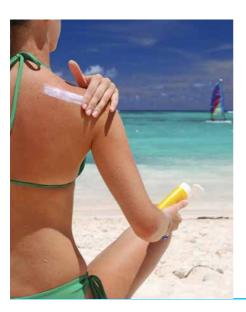
## How to prevent lymphedema?

Although there is no sure way to prevent lymphedema, some behaviors can reduce its risk or delay its emergence.

For example, it is known that the body responds to infection by producing extra fluids to combat it. Good body hygiene and careful skin care can reduce the risk of lymphedema by avoiding infections.

#### Hygiene

- Be careful when shaving the armpit on the operated side.
- Be careful when doing your manicure. Push back the cuticles, instead of cutting them.
- Use a daily moisturizer to help protect the skin from your hand and arm



#### Heat, cold and sun

- When cooking be careful for not burning yourself, for example with hot oil or boiling liquid.
- Avoid excessive heat like that found on saunas and hot tubs.
- Do not use a hot water bottle on the affected arm and shoulder.
- Take precautions to avoid sunburn. Use sunscreen with a protection factor of at least 30. Reapply frequently.
- Avoid extreme cold as it can cause the skin to break, increasing the chance of infection.

#### Grip and friction

- If you notice that your affected arm or hand is swollen, remove:
  - Anything tight or heavy, such as bags or coats.
  - Clothes with elastic bands tight enough to leave a body marks.
- Prevent skin friction. Do not use bags or anything with shoulder straps. Do not wear tight bras.
- Use your unaffected arm for injections, blood tests, or to check the blood pressure.
- If you had the lymph nodes on both sides removed, ask your doctor what would be the safest arm to use for procedures. He(s)he may even suggest using your leg instead.

#### Posture and physical activity

Use your affected arm as normally as possible (for hair combing, bathing, eating, or dressing), but avoid repetitive and vigorous activities such as lifting or pulling.

- Use your unaffected arm as much as possible (or use both arms) to carry heavy packages, shopping bags or handbags, to pick up children or even ironing.
- Discuss with to your doctor or physiotherapist a regular exercise program.
- × Avoid losing weight.

#### General recommendations

- Avoid anything that causes the skin to break as this can lead to infections.
- Use insect repellent to avoid being bitten.
- Use gloves when gardening, cleaning or washing the dishes.



# If you get a cut, scrap or burn:

- Wash the area with soap and water. Apply an over-the-counter antibiotic cream or lotion.
- Check with your doctor, nurse or pharmacist if you are not sure what to use.
- Cover with a clean, dry bandage or gauze. Keep the area clean and covered until it heal. Change the gauze every day or if wet.
- In burns, apply cold water (or an ice pack) for 15 min. Then wash with soap and water, and cover with a clean, dry bandage.
- Check daily for signs of infection such as pus, rash, redness, swelling, heat in the injured site or sensitivity, and chills or fever.
- Tell your doctor right away if you think you might have an infection.



# Control

## What to do to control lymphedema?

Although there is no cure for the condition, the following precautions, done as quickly as the problem is identified, can prevent its aggravation:

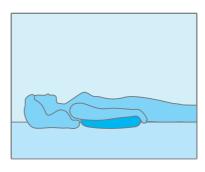
- Exercise -Talk to your doctor or physiotherapist about a regular exercise program. Avoid intense workouts that might tire excessively the affected shoulder or arm. Your health care team can help finding the right exercise plan for you.
- Raise the arm Keeping the affected arm and hand raised (see pictures) above the level of the heart, helps reducing the swelling, especially one recently developed.
- x Identify in which circumstance the swelling eases/worsens so to better control it.
  - Does it feel like you are swollen in the morning when you wake up? Is it worse at the end of the day, after using it?
  - Pay attention to your arm movements. If the arm is swollen or becomes uncomfortable stop and rest.
- If you travel on long-haul or frequent flights use a compression sleeve. A tightly fitting elastic sleeve can prevent swelling. However, it is crucial that the compression level is right, as anything too tight can interfere with lymphatic circulation.
  - Ask your doctor or physiotherapist if you should use a sleeve during the flight, and how to do it properly. When using an elastic sleeve for the first time be sure to try it before the flight in case it doesn't fit properly.
  - Your doctor or physiotherapist can also advise on how to keep the arm raised above the heart level and exercise safely during long haul flights.

Some people find that using the arm helps reducing the swelling. Others, that activities increase lymphedema. Be particularly alert to any swelling when doing things that require effort, such as carrying heavy bags, typing, or even chopping vegetables.

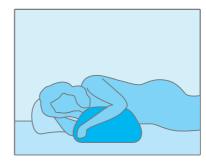
When you are seated, rest the affected arm on cushions or on the back of the sofa. This should put the arm above the level of the heart. Do not keep your arm above your head for long periods so it can rest.



If you lie on your back, rest your arm on one or two pillows by your side.



If you can sleep lying on the opposite side of the surgery, put one or two cushions in front of you and rest your arm on them.



## Treatment

There is no medication to treat lymphedema. The antibiotics prescribed are for infections. However, a good lifelong management of lymphedema can be done using Complete Decongestive Therapy.

## Complete decongestive therapy (CDT)

Also called complex physical therapy, is a program that combines many useful approaches from skin care, massage and exercise to the use of special bandages and compression sleeves. The treatment can be intensive or simpler depending of problem. A trained physiotherapist can help you choosing the plan that suits you best.

#### There are four components to CDT:

× Skin care

#### × Compression

Compression therapy is used to push the extra fluid out of the limb and prevent further accumulation. It can be done using elastic sleeves or pneumatic compression (with a pump).

#### x Exercise

The right exercise program can help by stimulating lymphatic vessels and increasing circulation. It is important to increase the exercises gradually to avoid tiring the arm.

#### × Manual lymphatic drainage (MLD)

A type of gentle massage believed to stimulate the lymphatic system. Vigorous massages, on the other hand, can lead to fluid production: avoid them in your affected arm or hand.

## Lymphedema complications

#### Infection

An infection in a patient with lymphedema can be extremely serious, because not only it tends to be harder to treat, but also to progress faster than normal. This because the viscous lymph fluid is ideal for bacteria to grow, while the lymph nodes, which help fighting infections, are compromised/missing in most patients with lymphedema.

To make things worse, the infection can also aggravate lymphedema, for example by damaging lymphatic vessels, compromising even more circulation.

In conclusion do not delay contacting your doctor if you notice any of the following signs of infection: pus or a rash on the affected arm, a fever or increased sensitivity, redness, swelling or warmth around the injured site.

#### Pain

Pain or abnormal sensitivity is not necessarily caused by lymphedema. However, lymphedema may lead to problems that cause pain. Contact your doctor to make a diagnosis if you have pain.



Unlike other side effects, like those that appear from drugs, there is no exact time frame for the development of lymphedema. It can appear shortly after surgery, months or even years after it (as much 20 years sometimes).

Because it is a condition without treatment, it is called chronic. However, it is normally just a light swelling, and easily controlled. Nevertheless, it is indispensable to take good care of it to assure that it does not get worse over time.



# PATIENT INFORMATION LEAFLETS ARE NOT MEANT TO REPLACE THE INFORMATION, ADVICE AND SUPPORT PROVIDED BY YOUR DOCTOR

Sources: American Cancer Society, Sloan Kettering Cancer Center, Mayo Clinic and recent research papers / Scientific Review: Maria Rita Dionísio, Médica Oncologista, Fundação Champalimaud / Content: Susana Lamas, Dr Catarina Amorim / Project coordination: Filipe Santos Silva / Design: www.sestudiorjdesign.com / Illustrations: www.zecardoso.com / Project by: Public Awareness of Cancer Unit, IPATIMUP October 2018 / + info: www.cancronafamilia.org















