

# Lymphoedema

Lymphoedema happens when lymph cannot flow through the body properly. Lymph builds up and causes swelling. Some swelling usually occurs after surgery but will settle down after a period. This is not the same as lymphoedema.

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### What is lymph?

Lymph is fluid from the body's tissues, and contains proteins, water, salts and white blood cells.

Lymphatic vessels carry lymph through the body to the lymph nodes. Here is where harmful substances, such as bacteria, are filtered out and destroyed. This helps to protect the body from infection. There are lymph nodes all around the body, including in the neck, armpits, chest, abdomen (stomach area), and groin.

Lymph, lymph nodes and lymphatic vessels are all part of the lymphatic system. Organs such as the tonsils, spleen and adenoids are also parts of the lymphatic system.

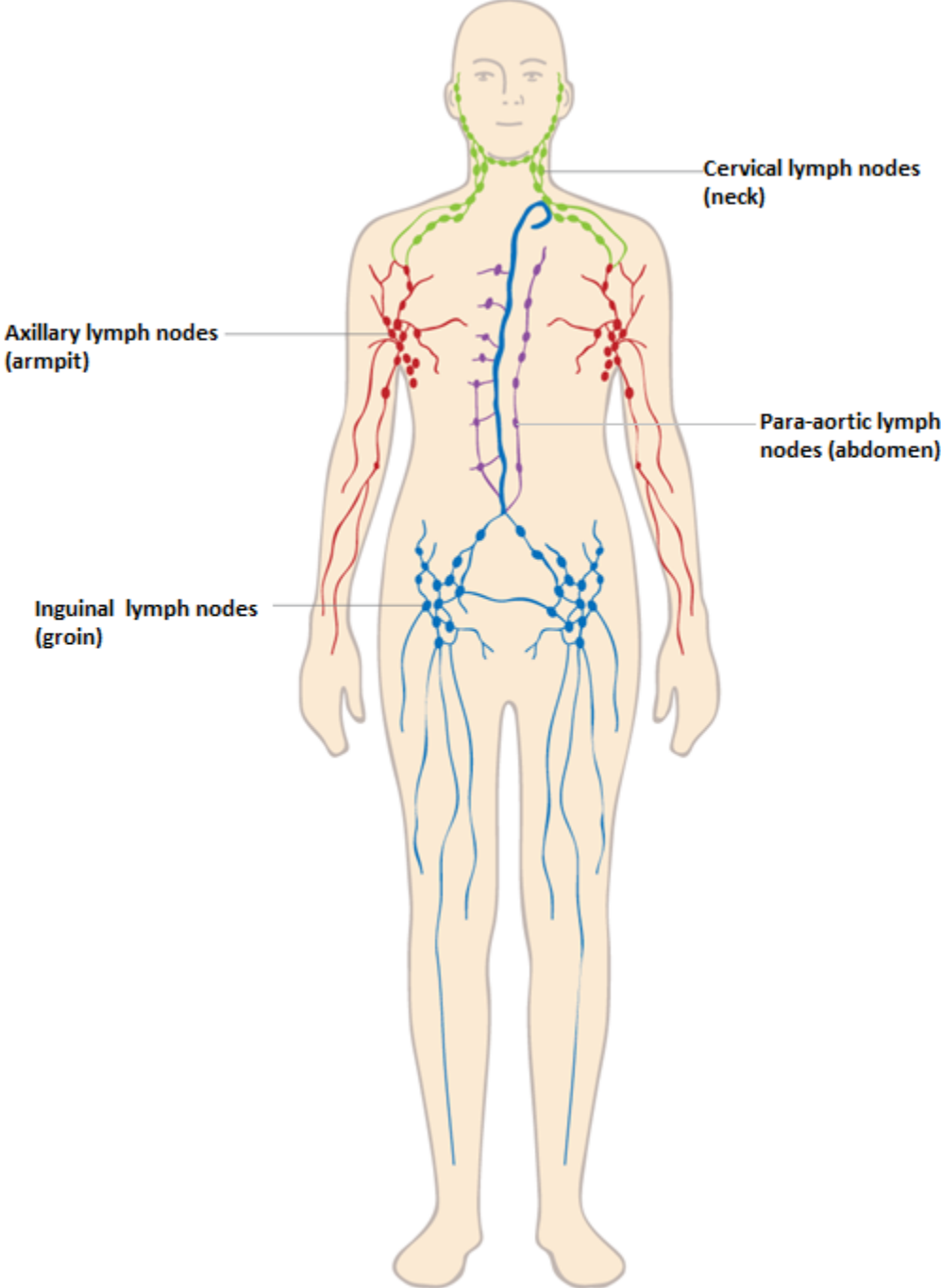
There are 2 types of lymphoedema.

**Primary lymphoedema** is a rare inherited condition in which lymph nodes and lymph vessels are absent or abnormal. This type of lymphoedema is not related to cancer treatment.

**Secondary lymphoedema** can occur after treatment for cancer, when lymph nodes are removed during surgery or damaged by radiotherapy. This can stop the lymph from flowing freely through the lymphatic system and can cause fluid to build up in some parts of the body. Sometimes, cancer itself can cause lymphoedema, if the tumour presses against or blocks the lymphatic system.

Lymphoedema usually develops gradually and can develop months, or even years, after your cancer treatment.

The lymphatic system



## Risk factors

Key risk factors for developing lymphoedema because of cancer include:

- having lymph nodes removed during surgery, especially if you've had several lymph nodes removed
- having radiation therapy that scars lymph nodes or lymphatic vessels
- having surgery or radiation therapy to areas that affect the lymph nodes
- being overweight or obese
- having a tumour that blocks or affects part of the lymphatic system.

Lymphoedema can happen after any type of cancer or treatment, but it most commonly affects:

- people with breast cancer who have had all or part of their breast removed, and axillary (underarm) lymph nodes removed
- people who have had surgery for pelvic area cancers such as uterine cancer, vulvar cancer, ovarian cancer, prostate cancer,
- people who have had surgery for melanoma
- people with head and neck cancers who have had high-dose radiation therapy and surgery to the head and neck region.
- People with lymphoma or leukaemia.

A technique called sentinel node biopsy can assist to reduce the number of lymph nodes removed at surgery. Sentinel node biopsy allows sampling of lymph nodes at the time of surgery for the presence of cancer. This is associated with a lower chance of developing lymphoedema than removing several or all lymph nodes.

For more information on these types of cancers see:

- [Breast cancer](#)
- [Head and neck cancer](#)
- [Leukaemia](#)
- [Lymphoma](#)
- [Melanoma](#)
- [Ovarian cancer](#)
- [Prostate cancer](#)
- [Prostate cancer](#)
- [Uterine cancer](#)
- [Vulvar cancer](#)

## Symptoms

Lymphoedema usually affects the arms, legs or face, depending on where the damaged or removed lymph nodes are.

Symptoms of lymphoedema include:

- swelling
- skin that feels very tight, warm, hard or thick
- skin that looks red or shiny, or dimpled like an orange peel
- trouble moving the arms or legs, or a joint in the arms or legs
- a feeling of heaviness in an arm or leg
- indents in the skin after wearing items like socks, rings, bracelets or watches
- pain or discomfort.



***Lymphoedema in the arm (left) and leg (right)***

If you have had treatment for head or neck cancer, symptoms of lymphoedema include:

- skin problems, as described for the arms and legs
- swelling in the face
- trouble moving the jaw, neck or shoulders
- problems with seeing properly
- drooling
- blocked nose or sinuses
- problems with eating, swallowing or breathing.

## Stages of Lymphoedema

*International Society of Lymphology (ISL) Lymphoedema Staging*

- **Stage 0:** A subclinical state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years before oedema becomes evident.
- **Stage 1:** This represents early onset of the condition where there is accumulation of tissue fluid that subsides with limb elevation. The oedema may be pitting at this stage.

- **Stage 2:** Persistent pitting oedema is manifest and limb elevation alone does not reduce swelling.
- **Late Stage 2:** Persistent swelling, there may or may not be pitting as tissue fibrosis is more evident.
- **Stage 3:** The tissue is hard (fibrotic) and pitting oedema may be absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths develop. The most severe changes are also known as elephantiasis.

## Preventing and managing lymphoedema

Lymphoedema cannot be cured, but there are things you can do to reduce your risk of developing lymphoedema or help stop it from getting worse.

### Managing lymphoedema focuses on:

- reducing and controlling swelling
- keeping active to help fluids circulate in your body and improve the range of movement of the affected area
- caring for your skin to prevent infections.

It is important to manage lymphoedema. Without management and treatment, the chronic swelling may cause serious skin conditions like cellulitis or skin ulcers.

You may want to see a lymphoedema therapist if your lymphoedema is hard to manage yourself.

### Reducing and controlling swelling

There are several ways to help control swelling:

- Avoid overheating. For example, don't take hot baths, sit in spas and saunas, or exercise too much in hot weather.
- Wear loose clothing.
- Avoid standing or sitting for a long time at once.
- Rest and raise the swollen limb when possible.

### Keeping active

Slow, gentle exercise is best for controlling lymphoedema. This will also help you maintain a healthy weight, which is important for managing lymphoedema.

If you aren't sure about what type of exercise is best for you, ask your doctor or a lymphoedema therapist.

### Caring for your skin

Your skin is an important barrier against infection. Any cuts, scrapes or other wounds can allow bacteria in, which can cause an infection. An infection may cause or worsen lymphoedema.

Where possible, avoid using the arm on the side of your surgery for blood pressure measurements, injections, blood samples or intravenous drips. To date there is not enough evidence to be sure that these procedures can trigger lymphoedema, however it's best to take precautions.

See a doctor as soon as possible if any signs of an infection appear, such as redness or inflammation.

### **Tips for skin care**

- Use a non-perfumed moisturising cream such as sorbolene to keep skin supple and avoid drying it out.
- Use a soap-free alternative to regular soap.
- Clean any scratches, grazes or cuts immediately with an antiseptic solution. Then use an antibacterial cream and cover the area with a clean, dry adhesive dressing.
- Keep your fingernails and toenails clean.
- Use an electric razor for shaving instead of a wet razor.
- Avoid tattoos and body piercings.
- Think of ways that you can protect your skin. For example, wear gloves while washing dishes, gardening or handling pets.
- Keep feet covered when outside.
- Keep the area between your toes clean and dry.
- See a podiatrist to treat or prevent ingrown toenails.
- Wear sunscreen when outside.

## Complex lymphoedema therapy

If your lymphoedema can't be managed at home, your doctor may refer you to a qualified lymphoedema therapist. You may get an individualised treatment program, called complex lymphoedema therapy (CLT).

CLT reflects the way you would manage lymphoedema at home yourself, but it is more intense. It might also include some activities that you can't do yourself at home.

CLT varies because it is a program developed just for you. It might include:

- manual lymphatic drainage (MLD) massage
- self-lymphatic drainage – self-administered version of MLD
- compression
- lymph taping
- skin care
- education and advice for home care.

MLD is a special form of massage that helps stop fluid from building up. It involves long, slow, gentle massage strokes that help 'push' lymph from the swollen area to nearby or distant lymph nodes that are working properly.

### Compression

Gentle, even compression can help control swelling and encourage fluid to move through the lymphatic system. There are several ways compression can be applied.

### Bandages

Compression bandaging may also be called multilayered lymphoedema bandaging (MLLB). It is usually done after MLD.

MLLB helps to drain the built-up fluid and to stop it from building up again. It involves putting on several layers of different types of bandages.

A lymphoedema therapist should put on the bandages and replace them every day.

### Garments

Compression garments are tightly fitting elastic garments worn on the swollen area. Wearing a compression garment can help to reduce swelling by stopping fluid from building up and by moving excess fluid out of the affected area.

Your lymphoedema therapist may suggest wearing a compression garment when there is swelling, or when you're exercising or flying in a plane. Compression garments should be fitted professionally and replaced when they lose their elasticity (usually after about 6 months). Your compression garment should have a snug fit, but not be uncomfortable.



## **Pumps**

Compression pump therapy is also called sequential intermittent pneumatic compression (SIPC). It involves wearing special garments that are attached to an air pump and can fill up with air, like a blood pressure cuff. You can control the amount of air going into the garments – the more air in, the tighter the pressure.

If your lymphoedema therapist feels you will benefit from this therapy, they will show you how to use it at home.

## **Lymph taping**

Your lymphoedema therapist might suggest lymph taping. This uses kinesiology tape to help lymph fluid drain from the swollen areas.

## **Education**

Your lymphoedema therapist can advise you about anything you need to know to help manage your lymphoedema at home. This might include how to:

- do special limb exercises
- exercise gently and safely
- do some simple massage yourself
- use your compression garments or pumps
- take care of your skin.

## Treating lymphoedema

If you have lymphoedema and the swelling gets worse quickly or becomes red and warm, see a doctor urgently. Let the doctor know that you have lymphoedema and you might have an infection called cellulitis. Cellulitis is an infection of the skin and underlying tissue that needs to be treated with antibiotics.

Your doctor and lymphoedema therapist may advise you to:

- rest in bed and elevate the affected limb
- continue use of a compression garment, if comfortable and tolerable
- stop lymphatic drainage if it is part of your routine care, until the cellulitis goes away.

Even minor skin conditions such as tinea, eczema or another type of dermatitis should be treated as soon as possible. These can make the lymphoedema worse and increase your chance of infection.

### Good to know

- Diuretics do not help with the symptoms of lymphoedema.
- Some medications may make lymphoedema worse, such as steroids and some blood pressure medications. Be sure to discuss with your doctor any medications you are taking.
- If you are interested in trying alternative and complementary medicines, discuss this with your doctor or lymphoedema therapist. There is limited evidence to support many of these, and you want to make sure you don't try something that can make your lymphoedema worse.
- Surgery may be an option for some people, if nothing else has worked. Surgical techniques can include liposuction or microsurgery to bypass blocked lymphatic vessels.
- Laser therapy might help soften scar tissue and improve the function of the lymphatic vessels.
- Research is ongoing into methods for preventing, diagnosing and managing lymphoedema. Talk to your doctor or lymphoedema therapist about new treatments.

## Living with lymphoedema

If you have feelings of anxiety or depression that are overwhelming you, talk to your doctor or therapist. Treatments are available that can help.

You may find it helpful to talk to a specialist such as a counsellor or psychologist about how you are feeling.

Having lymphoedema may cause a range of feelings. You may feel upset or embarrassed about how your body looks, and it may affect the way you feel about yourself and your relationships with others. For some, the physical effects of lymphoedema can also affect lifestyle and work.

If you are diagnosed with lymphoedema, you might be upset or sad. Talking to others can help. You may find it helpful to talk to those close to you and let them know how you are feeling. You may prefer to talk to a member of your treatment team, such as your doctor or lymphoedema therapist. Sharing your feelings with other people who also have lymphoedema can help.

The [Cancer Council Helpline](#) on 13 11 20 can let you know about cancer support groups in your area.

### Questions to ask your doctor

- How can I help to prevent lymphoedema from developing after my surgery or radiotherapy?
- Who should I contact if I have concerns about my lymphoedema?
- What treatment do you recommend for my lymphoedema?
- What is the evidence that the treatment you are recommending will work?
- Can you refer me to a qualified lymphoedema therapist? How much will it cost to see a lymphoedema therapist?
- Where can I get a compression garment fitted? When should I wear my compression garment? How much will my compression garment cost?
- What type of moisturiser should I use?
- Can I keep some antibiotics at home?
- Who should I contact if I notice signs of an infection?
- What types of exercises can I do?
- Is there anything I can do at home to help my lymphoedema?
- Will lymphoedema affect my work or lifestyle?
- If I change doctors, should I tell them about my cancer treatment?
- Can I talk to someone about how I am feeling?

## For health professionals

### National guidelines

[Australasian Lymphology Association](#)

### State and territory clinical practice guidelines

NSW Agency for Clinical Innovation (2018). [Lymphoedema: a guide for clinical services](#)

[Queensland Health lymphoedema clinical practice guideline 2014: the use of compression in the management of adults with lymphoedema](#)

### International resources

National Cancer Institute (2023). [Lymphedema \(PDQ®\) – health professional version](#)

American Society of Clinical Oncology Educational Book (2020). [Avoiding the swell: advances in lymphedema prevention, detection, and management](#)

American Physical Therapy Association (2017). [Diagnosis of upper quadrant lymphedema secondary to cancer: clinical practice guideline from the Oncology Section of the American Physical Therapy Association](#)

### Literature reviews

O'Donnel, TF, Allison, GM, Iafrati, MD (2020). A systematic review of guidelines for lymphedema and the need for contemporary intersocietal guidelines for the management of lymphedema. *Journal of Vascular Surgery Venous and Lymphatic Disorders* 8(4):676–684. <https://doi.org/10.1016/j.jvsv.2020.03.006>

### Further education

Cancer Council NSW. [Understanding lymphoedema](#) (YouTube)

edCan. [Lymphoedema](#)

eviQ. [Lymphoedema module](#)

Macquarie University. [Lymphoedema: monitoring & intervention after breast cancer online course](#)

[MQ Health's Australian Lymphoedema Education, Research and Treatment \(ALERT\) Program](#)

## **Relevant links**

[Australian Lymphology Association](#)

[Lymphoedema Association Australia](#)

[Cancer Council NSW](#)

[Cancer Council Australia](#)