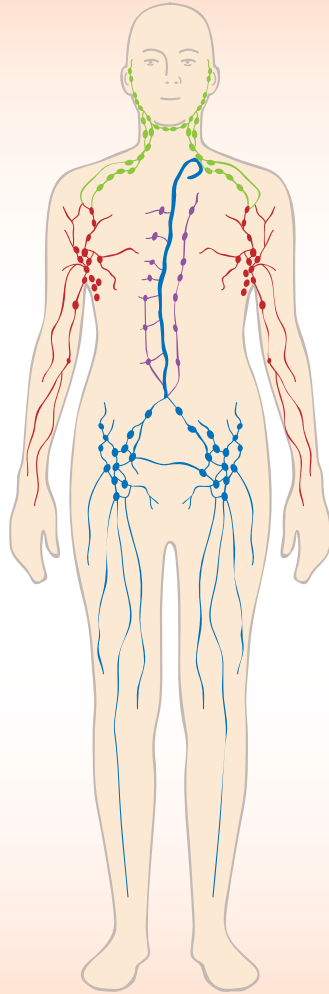


Lymphoedema

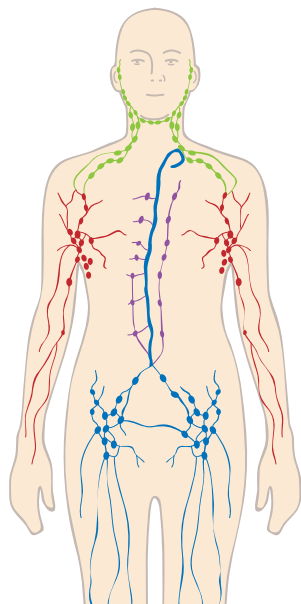
what you need to know



Australian Government
Cancer Australia

Lymphoedema

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Lymphoedema — what you need to know

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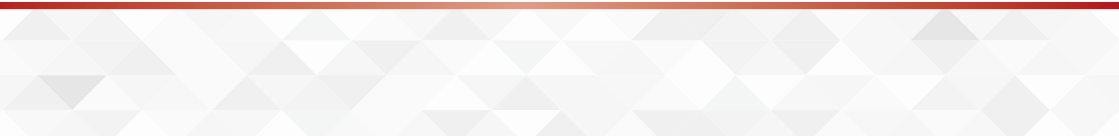
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** On 30 June 2011, National Breast and Ovarian Cancer Centre (NBOCC) amalgamated with Cancer Australia to form a single national agency, Cancer Australia, to provide leadership in cancer control and improve outcomes for Australians affected by cancer.*



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This information has been developed to help you understand the signs and symptoms of lymphoedema following treatment for cancer and what you can do to help manage the condition if you develop it.

What is lymphoedema?

Fluid from the body's tissues usually drains into lymphatic vessels, which are close to blood vessels. This fluid is called lymph. Lymphatic vessels carry the lymph fluid to lymph nodes where substances that could be harmful, such as bacteria, are filtered out and destroyed. This helps to protect the body from infection. The lymph then passes back into the main blood vessels. There are lymph nodes all around the body, including the armpit, groin, abdomen, chest and neck.

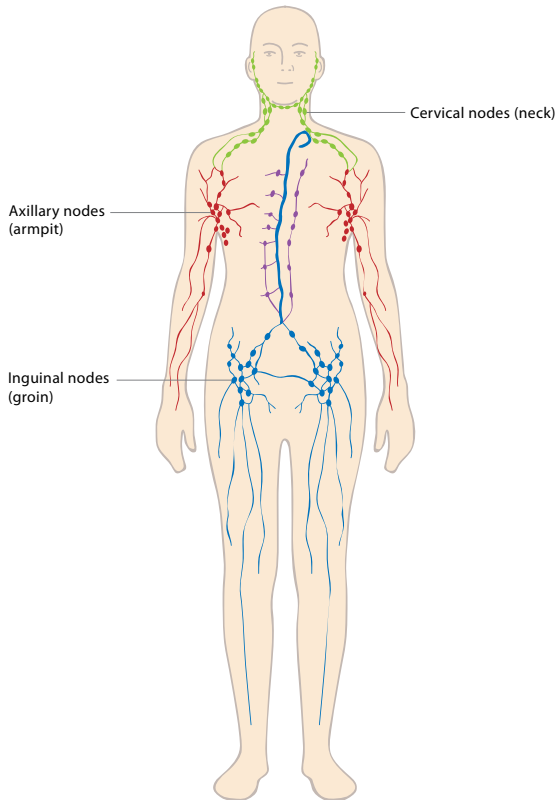


Figure 1: Diagram of the lymphatic system

Primary lymphoedema is a rare inherited condition in which lymph nodes and lymph vessels are absent or abnormal.

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

Lymphoedema may affect the arm after treatment of nodes in the armpit, or swelling may occur in the leg if nodes in the groin are removed. Facial swelling may also occur if local nodes are affected.

Information in this booklet focuses on secondary lymphoedema only.

Lymphoedema is not the same as the swelling or pain that immediately follows surgery and radiotherapy to the lymph nodes.

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



Figure 2: Lymphoedema in the arm following breast cancer treatment (Courtesy of The Australian)



Figure 3: Lymphoedema in the leg following cervical cancer treatment (Courtesy of Royal Adelaide Hospital)

How common is lymphoedema?

Conservative estimates suggest that at least 20% of patients treated for melanoma, breast, gynaecological or prostate cancers will experience secondary lymphoedema.

Reducing the risk of lymphoedema

The risk seems to be higher for people who have several lymph nodes removed and for those who have both surgery and radiotherapy to the lymph nodes.

Studies investigating risk reduction of lymphoedema have focused on surgical or radiotherapy techniques that are less damaging to the lymphatic system. These include:

- ▶ a technique called **sentinel node biopsy**, where only a limited number of draining lymph nodes are removed from the armpit/groin to check whether cancer has spread outside the breast or relevant limb. This technique is associated with fewer problems of swelling, movement and sensation than removal of all the lymph nodes from the armpit or groin (called an **axillary or inguinal clearance**)
- ▶ methods to limit the amount of radiotherapy given to the lymph nodes.

Most people who have lymph nodes removed or radiotherapy to the lymph node region will not develop lymphoedema.

Signs and symptoms

What are the signs and symptoms of lymphoedema?

Early signs and symptoms of lymphoedema to look for include:

- ▶ a feeling of heaviness, tightness or fullness in the limb or body part
- ▶ swelling (you may notice indentations in the skin from tight clothing, jewellery or shoes)
- ▶ ache, pain or tension in the limb or body part.

Some of these early signs and symptoms may come and go. If you notice one or more of the changes above, you should discuss these with your doctor.

How is lymphoedema managed?

There is no known cure for lymphoedema, but it can be managed with appropriate care.

The aim of management is to reduce and control swelling, improve the range of movement of the affected area and prevent infections.

General advice if you have developed or are at risk of developing lymphoedema includes:

- ▶ **Skin care** — daily attention to skin care is essential as the skin provides a protective barrier against infection (see 'Tips for managing your lymphoedema').
- ▶ **Exercise** — general exercise will help your mobility and maintenance of a healthy body weight.

Talk to your doctor about what additional treatment options may be suitable for you.

Your doctor may refer you to a qualified lymphoedema practitioner for an individualised treatment program, often referred to as complex physical therapy (CPT). A lymphoedema practitioner is an occupational therapist, physiotherapist or nurse who is specifically trained to treat lymphoedema.

The treatments recommended will vary depending on the stage of the lymphoedema and the severity of symptoms.

Components of CPT include:

- ▶ **Compression garments** — these are tightly fitting elastic garments worn on the affected area. Studies suggest that wearing a compression garment can help to reduce the swelling associated with lymphoedema by stopping fluid from building up and by moving excess fluid out of the affected area. Wearing a compression garment may be recommended at times when swelling is present, or during certain activities such as sport or air travel. It may be combined with other forms of treatment such as manual lymphatic drainage (see opposite). Compression garments should be fitted professionally and replaced when they lose their elasticity.



Figure 4: Application of compression garment to the arm

- ▶ **Manual lymphatic drainage (MLD) or decongestive physiotherapy** — this is a special form of massage of the affected area that aims to improve the way in which the lymphatic vessels are working and helps reduce the build-up of fluid. It includes long, slow, gentle strokes that stimulate the flow of lymph from the affected area through the remaining lymph vessels to nearby or distant lymph nodes. Such treatments should be designed by a qualified lymphoedema practitioner, who can also teach your family members this specialized technique.
- ▶ **Special limb exercises** — many of these exercises for the affected limb can be taught to you or a carer, and may be done at home.
- ▶ **Elevation** — raising the limb, for example by supporting the arm or leg on several pillows, can help reduce the symptoms of lymphoedema in the early stages of the condition.
- ▶ **Compression bandaging** — is usually done in combination with MLD, to reduce severe swelling prior to the fitting of a compression garment or if the skin is very fragile or damaged. These bandages should be replaced every day.

Treating infections

If you have lymphoedema and the affected area swells quickly or becomes red and warm, you will need to arrange an urgent appointment with your doctor. You should let them know that you may have cellulitis (an infection of the skin and underlying tissue) that needs to be treated with antibiotics. Your doctor 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 has been resolved.

It is also important to treat skin conditions such as tinea, eczema or dermatitis as soon as possible, as they can also make the lymphoedema worse (see 'Tips for managing your lymphoedema').

Good skin care reduces the likelihood of cellulitis, and consequently the need for antibiotics.

Treatments for which there is little or no evidence of benefit

Drug treatments — it is important to note that:

- ▶ diuretics are not effective in reducing the symptoms of lymphoedema
- ▶ some medications may worsen lymphoedema. These include steroids and some blood pressure medications. Discuss this with your doctor
- ▶ drugs that contain chemicals called benzopyrones or bioflavonoids are also not effective for the treatment of lymphoedema.

There are a range of alternative treatment options that have been used in the treatment of lymphoedema, however research findings on their effectiveness are limited. These treatments include ultrasound therapy, hyperbaric oxygen therapy, vitamin E supplementation, microwave therapy, acupuncture and moxibustion, mulberry leaf, aromatherapy oils, magnetic fields, vibration and hyperthermia.

Research is ongoing into methods for preventing, diagnosing and managing lymphoedema. This research will help to provide more evidence-based information in the future. Talk to your doctor or lymphoedema practitioner about new developments.

Emerging treatments

- ▶ **Laser therapy** — studies have investigated the use of laser therapy to help soften scar tissue and improve the function of the lymphatic vessels. A small number of studies suggest that this treatment may have some benefits, but further research is needed to validate treatment doses and regimes.
- ▶ **Pneumatic pumps** — pneumatic pumps use single or multi-chambered pumps that engulf the limb, inflating and deflating at different cycles and pressures. A small number of studies suggest that this treatment may have some benefits, especially when combined with other treatments such as manual lymphatic drainage, compression garments and massage. However, further research is required to determine the most effective kind of pump, pumping time and pressure levels. If used inappropriately, this technique can cause damage to the soft tissue and make the lymphoedema worse.
- ▶ **Surgery** — surgery for lymphoedema is generally only recommended when other treatment options have not been effective. Surgical techniques can include liposuction or microsurgery to bypass blocked lymphatic vessels.

Coping with lymphoedema

If you develop lymphoedema you may experience a range of feelings in addition to the physical symptoms of the condition. 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, it is not uncommon to feel upset or sad. Most people find that these feelings ease with time, as they learn how to manage the condition.

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 practitioner. Sharing your feelings with other people who have experienced lymphoedema can also help. The Cancer Council Helpline on 13 11 20 can let you know about cancer support groups in your local area.

If you have feelings of anxiety or depression that are overwhelming you, talk to your doctor. Treatments are available that can help. You may find it helpful to talk to a specialist such as a counsellor, psychologist or sex therapist about how you are feeling.

Questions to ask your doctor

Listed below are some questions you may like to ask your doctor or lymphoedema practitioner.

- ▶ 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 practitioner?
- ▶ How much will it cost to see a lymphoedema practitioner?
- ▶ 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?
- ▶ Are there any techniques I can use at home to help my lymphoedema?
- ▶ How might my work be affected?
- ▶ How might my lifestyle be affected?
- ▶ If I change doctors should I tell them about my cancer treatment?
- ▶ Can I talk to someone about how I am feeling?

Tips for managing your lymphoedema

There are some actions that you can take to reduce your risk of developing lymphoedema or to help stop the condition from getting worse.

Caring for your skin is essential to prevent or control lymphoedema.

The skin is an important barrier against infection. If it is broken, bacteria can enter the body and cause infection. Any infection may cause or worsen lymphoedema in the affected area of the body.

Suggestions on how to keep your skin healthy and prevent infections include:

- ▶ keep the skin supple using a non-perfumed moisturising cream such as sorbolene
- ▶ avoid drying out your skin and consider using a soap-free alternative
- ▶ clean any scratches, grazes or cuts immediately using an antiseptic solution, use an antibacterial cream and cover the area with a clean, dry plaster
- ▶ use an electric razor for shaving instead of a wet razor
- ▶ avoid tattoos and body piercing
- ▶ consider ways that you can protect your skin. For example wearing gloves while washing dishes, gardening or handling pets.



Foot care is essential for people who have developed or are at risk of developing lower limb lymphoedema.

It is important to:

- ▶ keep feet covered when outdoors
- ▶ keep feet clean and dry between your toes; wear cotton socks
- ▶ check feet regularly for tinea or infection and treat promptly



- ▶ take care when cutting toenails; prevent ingrown toenails and infection
- ▶ wear well-fitting shoes to prevent calluses and corns
- ▶ see a podiatrist as needed.

It is essential that you keep active to help the circulation of fluid.

For example:

- ▶ follow a gentle exercise routine and if you want to exercise more vigorously, work up to this slowly and always warm down slowly
- ▶ talk to your doctor or a lymphoedema practitioner if you have questions about what activities are best for you
- ▶ maintain a healthy weight with regular exercise
- ▶ avoid long periods of inactivity.

Try to avoid activities that will put extra strain on the lymphatic system or stop lymph flow.

For example:

- ▶ sunburn to the affected area
- ▶ hot baths, spas and saunas
- ▶ strenuous exercise in hot weather
- ▶ poorly fitting or tight clothing and shoes.

It has been suggested that long-distance air, road or train travel may increase the risk of developing lymphoedema. While the evidence for this is not strong, it may be helpful to wear a compression garment and to perform gentle exercises while you travel.

It is currently unknown whether certain procedures such as blood samples, injections, intravenous drips and blood pressure monitoring increase the risk of lymphoedema. Therefore, as a precaution, use the unaffected limb for these actions whenever possible.

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

