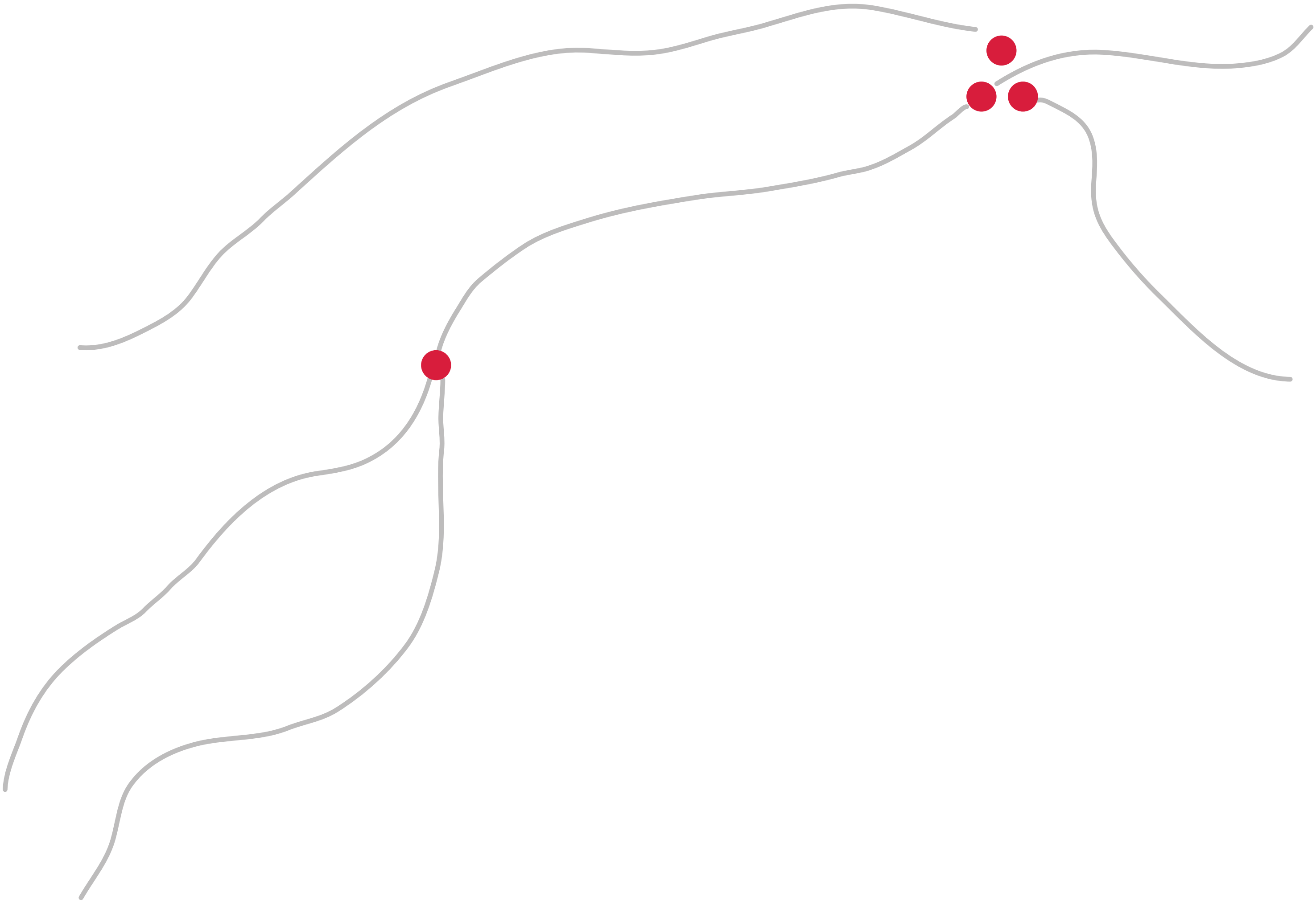
SECONDARY LYMPHOEDEMA

Patient Resource



HealthPathways Melbourne

VICTORIA State Government

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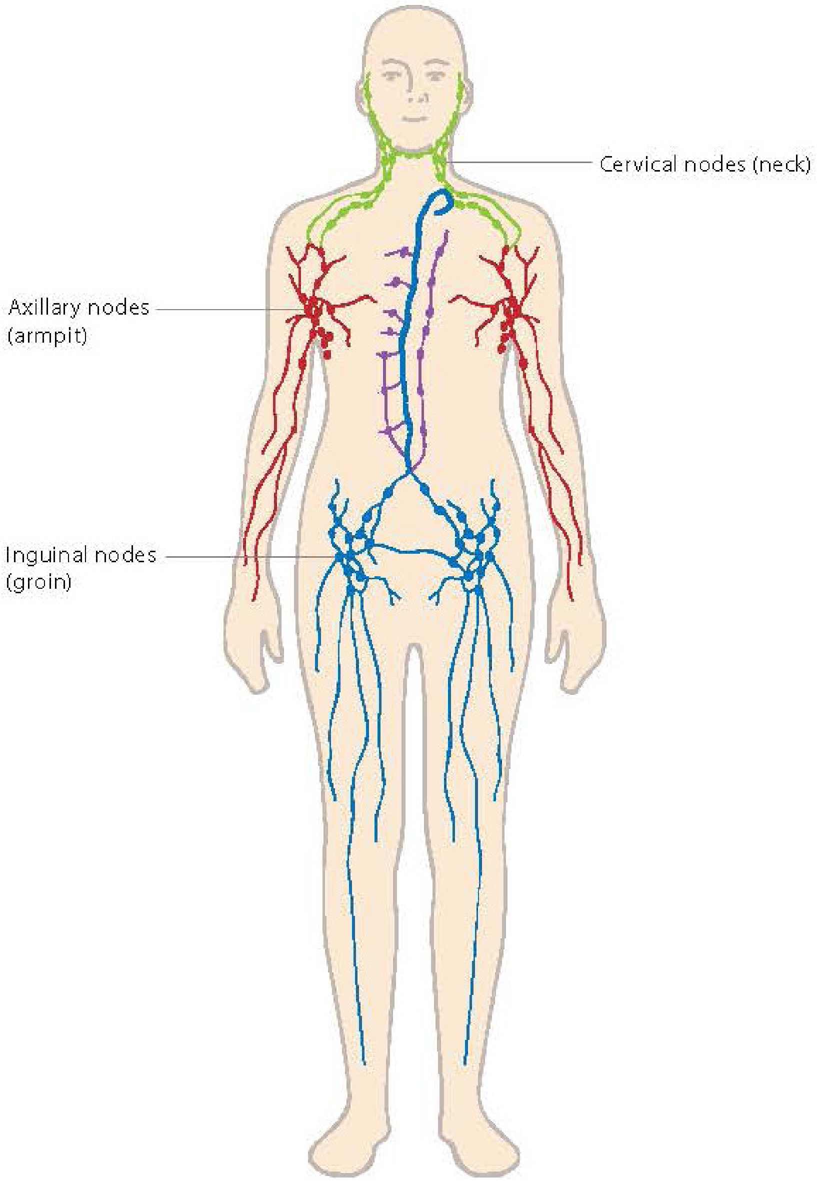
> This information has been developed to help you understand the signs and symptoms of lymphoedema following treatment for cancer and what you can do to help manage the condition if you develop it.

Contents

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 viruses, bacteria or cancer cells 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 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.

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

Information in this booklet is about secondary lymphoedema.

Secondary lymphoedema is not the same as swelling or pain in the first six weeks after surgery or radiotherapy to the lymph nodes.

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

Figure 2: Secondary lymphoedema in the arm following breast cancer treatment

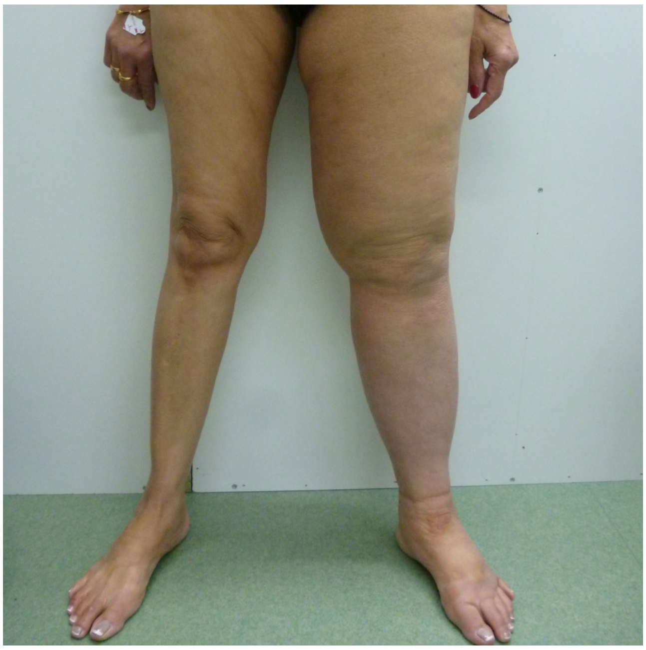


Figure 3: Secondary lymphoedema in the leg

How common is secondary lymphoedema?

About 20% of patients treated for melanoma, breast, gynaecological or prostate cancers will experience secondary lymphoedema. This means that 80% of patients will not develop this condition.

Reducing the risk of secondary 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.

Treatments to reduce damage to the lymphatic system include:

- **Sentinel node biopsy**, where one to four draining lymph nodes are removed from the armpit/groin to check whether cancer has spread. 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.

> Keep in mind, most people who have lymph nodes removed or radiotherapy to the lymph node region will not develop secondary lymphoedema.

Signs and symptoms

What are the signs and symptoms of secondary lymphoedema?

Early signs and symptoms of secondary 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 at your next appointment.

How is secondary lymphoedema managed?

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 secondary 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 secondary lymphoedema').
- **Exercise** — exercise will help your mobility and keep you at a healthy body weight. Exercise will also improve lymphatic flow and reduce your swelling.
- **Weight gain** — may worsen your lymphoedema.

Talk to your doctor about what additional treatments may be helpful for you.

Your doctor may refer you to a registered lymphoedema practitioner for a personalised treatment program, also called Complex Lymphoedema Therapy (CLT). A registered lymphoedema practitioner can be an occupational therapist, physiotherapist or nurse who is specifically trained to treat lymphoedema.

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

Components of CLT include:

- **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 secondary lymphoedema in the early stages of the condition. Rest or sleep on a bed overnight so you can keep your legs up. Sleeping in a chair will make leg swelling worse.
- **Manual lymphatic drainage (MLD) or decongestive physiotherapy** — this is a special form of massage of the affected area that improves the way 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. Such treatments should be designed by a qualified lymphoedema practitioner, who can also teach your family members this specialised technique.

- **Compression garments** — these are tightly fitting elastic garments worn on the affected area. Wearing a compression garment can help to reduce the swelling of secondary lymphoedema by stopping fluid from building up and by moving excess fluid out of the affected area. Wearing a compression garment may be recommended when swelling is present, or during activities such as sport or air travel. It may be combined with other treatment such as manual lymphatic drainage (see above). Compression garments should be fitted professionally and replaced when they lose their elasticity, usually every six months. They are worn during the day.

Figure 4: Application of compression garment to the arm

- **Compression bandaging** — is usually done in combination with manual lymphatic drainage (MLD), to reduce severe swelling before the fitting of a compression garment or if the skin is very fragile or damaged. These bandages should be replaced regularly.

Treating infections

If you have secondary lymphoedema and the affected area swells quickly or becomes red and warm, you may have cellulitis (a severe infection of the skin) that needs to be treated with antibiotics.

You will need to call your doctor to book a same day urgent appointment.

Your doctor may advise you to:

- start antibiotics immediately or send you to the hospital emergency department for intravenous antibiotics
- rest in bed and elevate the affected limb
- not to wear your compression garment during severe infection if increased swelling makes the garment too tight.
- stop manual lymphatic drainage if it is part of your routine care, until the cellulitis is gone.

It is also important that skin conditions such as tinea, eczema or dermatitis are treated as soon as possible, as they can make your secondary lymphoedema worse (see ‘Tips for managing your secondary lymphoedema’).

> Good skin care reduces the chance of cellulitis, and the need for antibiotics.

Treatments with little or no benefit

Drug treatments — it is important to note that:

- fluid tablets do not reduce the symptoms of secondary lymphoedema
- some medications may worsen secondary lymphoedema. These include steroids and some blood pressure medications. Discuss this with your doctor.
- drugs that contain chemicals called benzopyrones or bioflavinoids are also not effective for the treatment of secondary lymphoedema. Bioflavonoids are a polyphenic group of plant derived supplements used in alternate medicine, naturally occurring in most fruit (especially citrus), vegetables and herbs. Bioflavonoids are also found in tea, wine and chocolate.

There are a range of complementary or alternative care options that have been used in the treatment of secondary lymphoedema. However evidence on their use is 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.

Always discuss with your doctor before considering using complementary and alternative care as part of your health plan.

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

More information: **https://www.cancer.org.au/** and **www.lymphoedema.org.au**

Emerging treatments

Laser therapy — laser therapy may be used to help soften scar tissue and improve the function of the lymphatic vessels.

Pneumatic pumps — pneumatic pumps use an air pump and a blow up sleeve that wraps around the limb, inflating and deflating at different cycles and pressures. They are used with other treatments such as manual lymphatic drainage, compression garments and massage. Pneumatic pumps must be used carefully or they can cause damage to the soft tissue and make the lymphoedema worse.

Surgery — surgery for secondary lymphoedema may have a very limited role when other treatments have not been effective. Surgery may include liposuction or microsurgery to bypass blocked lymphatic vessels.

Coping with secondary lymphoedema

If you develop secondary lymphoedema you may experience a range of feelings in addition to the physical symptoms. You may be worried about how your body looks. This may affect the way you feel about yourself and your relationships with others. The physical effects of secondary lymphoedema may also affect your lifestyle, work and intimate relationships.

If you are diagnosed with secondary 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 secondary 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

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

- Who should I contact if I am worried about my secondary lymphoedema?
- What treatment do you recommend for my secondary lymphoedema?
- What is the evidence that the treatment 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?
- Is there anything I can do at home to help my secondary 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?
- Who can I talk to about how I am feeling?

Tips for managing your secondary lymphoedema

Things you can do to reduce your risk of developing secondary lymphoedema or to help stop the condition from getting worse.

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

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

How to keep your skin healthy and prevent infections:

- keep the skin supple using a non-perfumed moisturising cream
- avoid activities that dry out the skin such as washing with soap 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 dressing
- 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 look after:

Your feet

- keep your feet covered
- keep your feet clean and dry well between your toes and check for tinea pedis; cotton socks can help
- check your feet regularly for tinea or infection and treat promptly
- take care when cutting your toenails to prevent ingrown toenails and infection
- wear well-fitting shoes to prevent calluses and corns
- see a podiatrist as needed

Your hands and fingernails

- keep fingernails healthy
- don’t push back cuticle
- treat chronic paronychia (fungal infection)
- artificial nails can be a problem

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

For example:

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

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

Examples of activities to avoid include:

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

Long-distance air, road or train travel may increase the risk of developing secondary lymphoedema. It may be helpful to wear a compression garment and to perform gentle exercises while you travel.

It is currently unknown whether having blood samples, injections, intravenous drips and blood pressure monitoring in or on the affected limb increase the risk of secondary lymphoedema. As a precaution, ask that your unaffected limb is used for these actions whenever possible. Avoid immunisations in the affected limb.

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

Useful links and resources:

Better Health Channel www.betterhealth.vic.gov.au

Cancer Australia www.canceraustralia.gov.au

Cancer Council Victoria **13 11 20** | www.cancervic.org.au

Lymphoedema Association of Victoria (LCGP) **1300 852 850** | www.lav.org.au

Lymphoedema Compression Garment Program (LCPG) **1300 747 937 (1300 PH SWEP)** or **03 5333 8100** | https://swep.bhs.org.au/lymphoedema-compression-garment-program.php

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