

Living with lymphoedema



This information sheet was written for people with lymphoedema.

What is lymphoedema?

Lymphoedema is the swelling of part or parts of the body that occurs when the lymphatic system is not working properly. The lymphatic system consists of many tiny channels throughout the body called lymph vessels or lymphatics.

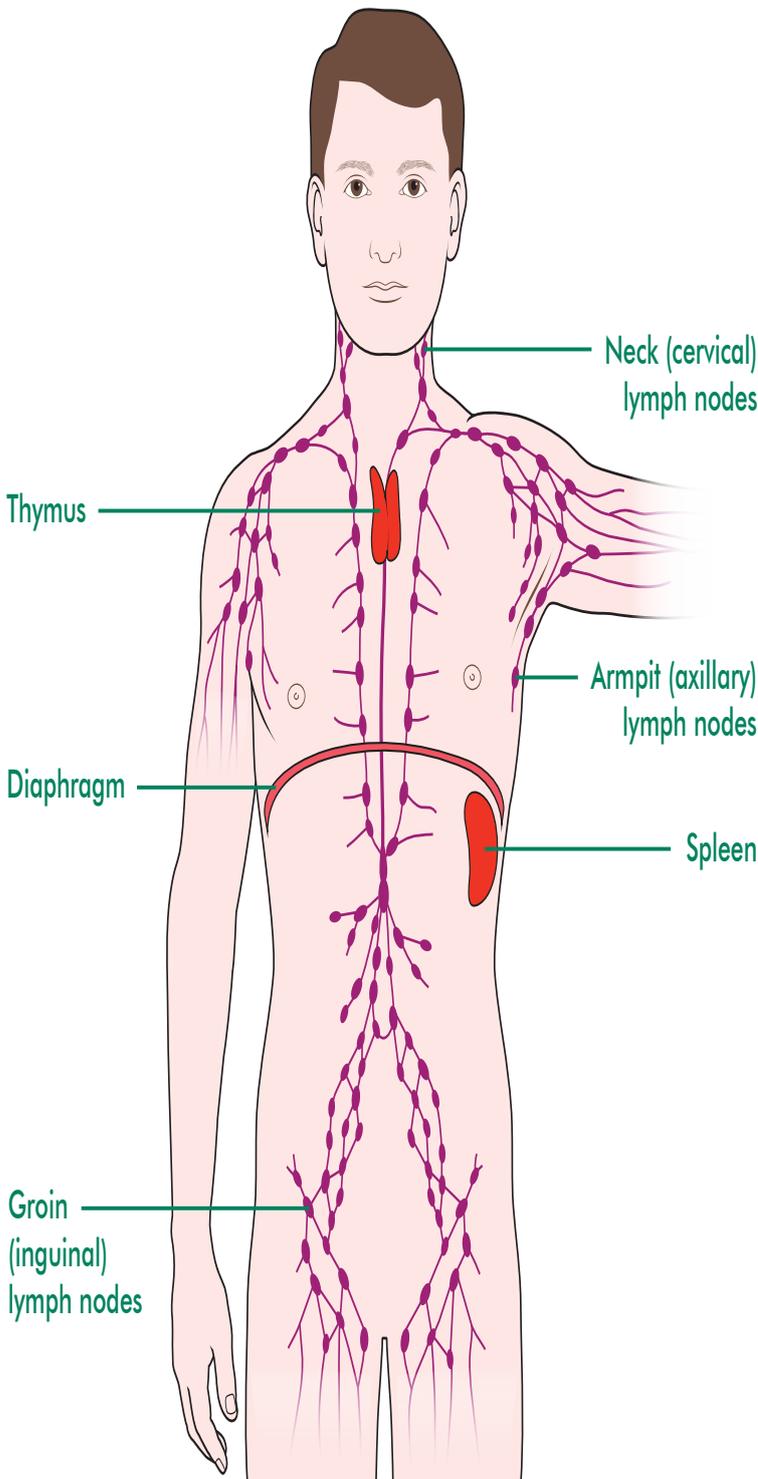
Like blood vessels, these join together to form larger channels. The lymphatic system carries lymph, a colourless, watery fluid that contains lymphocytes – a type of white blood cell. The lymph is filtered through a number of nodes (sometimes known as glands) before going into the bloodstream. Lymph nodes range in size from as small as a pinhead to as large as a baked bean. In some parts of your body there may be just a few, whereas in your armpit there are, generally, 30–50 nodes

Some factors that may cause lymphoedema are:

- birth abnormality, which may not show until later in life (primary lymphoedema).
- where lymph nodes are blocked, damaged or cut (secondary lymphoedema), for example:
 - after surgery to lymph nodes
 - radiation treatment to lymph nodes.

Not everyone who has the above treatments will develop lymphoedema, and of those who do, many will only experience mild swelling

- Lotion or QV moisturiser. These are non-sticky lotions (without lanolin or perfume). For dry scaly skin use a 10 percent urea cream, for example, Aquacare



Lymphoedema management

Lymphoedema is not curable. In most cases it can be controlled with treatment. See a lymphoedema therapist for an assessment and a treatment plan. Contact your local Cancer Society for a lymphoedema therapist in your area.

Treatment may include:

- massage
- compression
- skin care
- exercise

Skin care

Good skin care can help minimise the risk of infection

If build-up from lymphoedema sits close to the skin surface, the limb may become infected through cuts, scratches or insect bites.

See your doctor immediately:

- **if any pain, redness or heat is present in the affected limb.**
- **you notice any red lines tracking along the limb.**
- **if you feel generally unwell.**

Always complete the prescribed course of antibiotics. If signs and symptoms persist after a course of antibiotics, seek medical advice. The infection may not have completely cleared.

- Avoid sunburn, cover up and use 30+ sunscreen when outdoors.
- Keep skin soft – gently moisturise daily with a non-perfumed cream or oil, such as Dermaveen Moisturising
- Lotion or QV moisturiser. These are non-sticky lotions (without lanolin or perfume). For dry scaly skin use a 10 percent urea cream, for example, Aquacare.
- Instead of soap try a body wash, for example, QV wash soap alternative or Dove soap. They are nonlathering gentle cleansers that do not dry out the skin.
- Wear gloves when gardening or doing dishes.
- Try to avoid insect bites, cuts and scratches. Treat any that occur with antiseptic ointment or spray, for example, Savlon and, Stingose. You may be prescribed an antibiotic ointment, for example, Bactroban.
- If possible, use the unaffected arm to have your blood pressure, injections or blood taken.
- Avoid the use of hot water bottles, or ice or heat packs on your affected limb.
- Spa baths are not recommended.
- Always wear your compression garment as shown. If you

do not have a compression garment contact your local Cancer Society or your therapists. You may need to wear a garment for air travel or land journeys at high altitude, for example, tramping or long car journeys.

- For arm lymphoedema, use the unaffected arm for carrying heavy parcels.
- Check that your work environment is not making your lymphoedema worse (for example, computer set-up, heavy lifting or repetitive movements).
- For leg lymphoedema, avoid standing or sitting still for long periods. Do gentle exercises every 15 minutes, such as changing your leg position, bending, stretching, or circling your foot at the ankle. Try to get up and walk around every hour if possible.
- **Treat all infections, such as athlete's foot, promptly.**

Tips for diet

A balanced diet low in fat and high in fibre is important.

- Eat plenty of fresh fruit and vegetables.
- Drink lots of fluid daily, especially water.
- Try to maintain the ideal weight for your height and build.
- Putting on weight can make lymphoedema more difficult to control.
- Having low protein may worsen the condition. Eat easily digested protein, such as chicken, fish, tofu or low fat dairy products.

Tips for Exercise

Regular exercise, such as walking and swimming can be very good for you. Muscular action will help to move the fluid out of the swollen limb. See your lymphoedema therapist or local Cancer Society for exercise sheets that will help.

Tips for self-massage

Learn how to do this from your lymphoedema therapist.

Wearing compression garments

These should be fitted by a lymphoedema therapist or another trained person. They should be worn according to the therapist's instructions and cared for according to the manufacturer's instructions. Talk to your lymphoedema therapist about suppliers and subsidies that may be available.

Other support

Talking about your experience can be very helpful. Other people with lymphoedema can be a great source of support, advice and experience. Check with your local Cancer Society for local support groups or education in your area.

Lymphoedema therapists

These are usually nurses, physiotherapists or massage therapists who have undertaken specialised training in lymphoedema management. Check that your therapist has the appropriate training. Your local Cancer Society will be able to advise you about trained lymphoedema therapists in your area.

- Lymphoedema therapists work in public and private practice. Private costs may be covered by your medical insurance. You will need to check your policy if you have one.
- If your lymphoedema is moderate to severe, your lymphoedema therapist will probably recommend a course of Complex Physical Therapy (CPT). This can be successful in reducing and controlling swelling, and the earlier it is started in the development of lymphoedema, the higher the likelihood of success. CPT involves bandaging and massage (daily for 2–3 weeks), along with exercise, skin care, dietary advice and the fitting of a compression garment.

Seek treatment early: see a lymphoedema therapist early in the development of lymphoedema, or if there is any increase in existing lymphoedema.

Suggested websites for more information

The following organisations have websites with free information available online.

If you do not have access to the internet, contact the Cancer Information Helpline **0800 CANCER (226 237)** who can provide this information for you.

- The National Breast and Ovarian Cancer Centre (Australia)
www.nbocc.org.au/lymphoedema/
- The Lymphoedema Association of Australia
www.lymphoedema.org.au
- British Lymphology Society
www.lymphoedema.org/bls
- Lymphoedema Support Network
www.lymphoedema.org
- Flinders Medical Centre
www.flinders.sa.gov.au/lymphoedema/
- Lymph Notes.Com
www.lymphnotes.com