

Understanding Lymphoedema

A guide for people affected by cancer

This fact sheet has been prepared to help you understand more about secondary lymphoedema, a possible side effect of cancer treatments. In this fact sheet, the term lymphoedema refers to secondary lymphoedema. We hope this fact sheet will help you, your family and friends understand what lymphoedema is, how to recognise signs early and how it can be managed.

About the lymphatic system

The lymphatic system is part of both the circulatory and immune systems. It consists of:

Lymph vessels – A large network of thin tubes found throughout the body. Lymph vessels carry lymph fluid from our tissues, organs and structures to the lymph nodes.

Lymph fluid – This normally clear fluid travels to and from the tissues in the body, carrying nutrients and taking away bacteria, viruses, abnormal cells and cell debris.

Lymph nodes (glands) – Small, bean-shaped structures found along the lymph vessels. Lymph nodes are located throughout the body, including in the neck, underarms, chest, abdomen and groin. The lymph nodes filter lymph fluid as it passes through the body, before emptying most of the fluid into the bloodstream.

Other lymph tissue – As well as lymph nodes, lymph tissue is found in other parts of the body including the spleen, bone marrow, thymus, tonsils and some lymph tissue in the digestive tract.

The lymph fluid, lymph nodes and lymph tissue contain white blood cells called lymphocytes, which help protect the body against disease and infection.

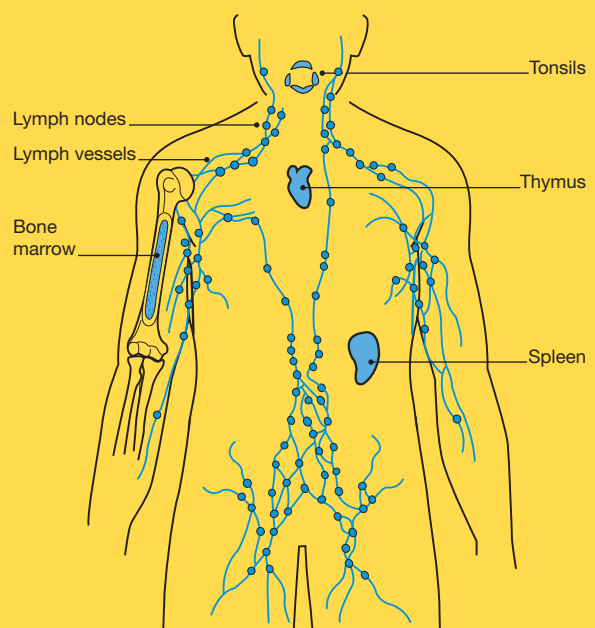
What is lymphoedema?

Lymphoedema is swelling (oedema) that develops when lymph fluid builds up in the tissues under the skin or sometimes deeper in the abdomen and chest areas. This happens because the lymphatic system is not working properly in that part of the body. It usually occurs in an arm or leg, but can also affect other parts of the body.

Lymphoedema can be either primary (when the lymphatic system has not developed properly) or secondary. This fact sheet is only about secondary lymphoedema following treatment for cancer.

Cancer or cancer treatment can damage or block the lymphatic system, which can stop the lymphatic system from working properly. This means that lymph fluid doesn't drain as it should and instead builds up in the tissues, causing swelling.

The lymphatic system



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When does lymphoedema develop?

Lymphoedema can affect people at any time – during active cancer treatment, after treatment or in remission. It can also develop while you're living with advanced cancer or during palliative treatment. Lymphoedema can occur months or years after treatment. It usually develops slowly.

What are the risk factors?

Whether or not you develop lymphoedema after treatment for cancer depends on the location of the cancer, its stage and the type of treatment. While the risk is lifelong, most people who are at risk never develop lymphoedema.

Some factors increase the risk:

- surgery to remove lymph nodes – the more nodes removed, the greater the risk of developing lymphoedema; having a sentinel lymph node biopsy reduces the chance of getting lymphoedema but it can still occur in a small number of people
- radiation therapy that causes scarring and thickening of the tissues and often the lymph nodes and lymph vessels
- taxane-based chemotherapy drugs (talk to your oncologist if you are concerned)
- an infection in the limb at risk of developing lymphoedema (i.e. the arm or leg on the side where the lymph nodes were removed)
- injury of the lymphatic system – for example, a tumour growing near a lymph node or vessel can block the flow of lymph fluid
- an existing problem with the lymphatic system (underlying primary lymphoedema)
- rheumatoid arthritis
- being overweight or obese
- not being able to move around easily.

See the How to reduce your risk of lymphoedema table on page 3 for tips on lowering the risk of developing lymphoedema.

How common is lymphoedema?

Lymphoedema can occur following treatment for many different cancers (see table next column). There is little statistical information about how common lymphoedema is following cancer

treatment. However, one Australian study estimated that lymphoedema occurs in over 20% of all cancer patients treated for gynaecological (vulvar/vaginal, ovarian, uterine and cervical), breast, prostate cancers or melanoma.¹

| Cancer type | Commonly affected areas |
|----------------|--|
| bladder | genitals, legs |
| breast | arm, hand, breast, chest, trunk |
| cervical | genitals, legs |
| head and neck | face, below chin and/or neck |
| melanoma | any part of the body such as face, neck, hand, forearm, upper arm or whole arm, breast and/or chest wall, legs |
| ovarian | genitals, abdomen/trunk, legs |
| prostate | legs, abdomen/trunk, genitals |
| uterine | legs |
| vulvar/vaginal | genitals, legs |

What are the early warning signs?

Because lymphoedema is easier to manage and treat in its early stages, it is important to look out for any signs that you are developing lymphoedema and to see your lymphoedema practitioner or doctor soon after they appear. If you are at risk of developing lymphoedema, see a lymphoedema practitioner for regular check-ups rather than waiting for signs to appear. Taking action at an early stage can help reduce the risk of developing lymphoedema and the severity of lymphoedema if it does develop.

You may have one or more of the following symptoms and/or signs in the affected area:

- feeling of tightness, heaviness or fullness
- aching in the affected area
- swelling that comes and goes or is more noticeable at the end of the day
- clothing, shoes or jewellery feeling tighter than usual
- not being able to fully move the affected limb
- pitting of the skin (when gentle pressure leaves an indent on the skin).

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If you are unsure whether any symptoms are an early sign of lymphoedema, contact a lymphoedema practitioner. You can ask your general practitioner (GP) or specialist to refer you to a lymphoedema practitioner for assessment or see How to find a lymphoedema practitioner on page 4.

If left untreated, lymphoedema can progress and cause a range of problems, including:

- trouble moving around and doing your usual activities
- discomfort and sometimes pain
- difficulty fitting into clothes or shoes
- an increased risk of infections and of small infections becoming more serious (see box, page 4)
- further hardening of the skin and other structures (fibrotic changes)
- lymph fluid leaking from the skin (this is known as lymphorrhea)
- very rarely, the development of lymphangiosarcoma, a soft tissue cancer.

How to reduce your risk of lymphoedema

There are several things you can do to help reduce your risk of developing lymphoedema after treatment. If you notice changes in the affected part of your body, see your doctor immediately. These suggestions are also useful for people living with lymphoedema.

Use the affected area normally

- Don't try to protect the affected limb by limiting its movement – moving the limb normally will keep the lymph fluid flowing.
- Avoid repeated heavy lifting, such as moving heavy boxes or furniture, as it may worsen your symptoms.
- Avoid pressure in the wrong place, such as a tight bra strap or underwear with tight elastic.
- Research shows that it is not necessary to wear a compression sleeve during airplant travel if you don't have lymphoedema.

Look after your skin

- Keep your skin clean. Wash with a pH-neutral soap and avoid scented products.
- Moisturise your skin every day. Dry and irritated skin is more likely to tear and break.
- Protect your skin – wear gloves for gardening, housework, handling pets; use insect repellent to prevent insect bites; avoid cutting or burning your skin when cooking; wear protective clothing, a broad-brimmed hat, sunglasses and sunscreen when in the sun.
- Seek medical help urgently if you think you may have a skin infection (see page 4).

Exercise regularly

- Keep physically active to help the lymph fluid flow.
- Do regular exercise such as swimming, yoga, bike riding, aquarobics, walking or running. Gardening and housework also count as exercise.
- It's okay to do resistance training – increase the weight and intensity gradually. Be guided by how your limb responds, and cool down slowly.
- Start any exercise slowly and build-up gradually.
- Visit an accredited exercise physiologist or physiotherapist to develop an exercise program.
- ▶ See our *Exercise for People Living with Cancer* booklet.

Maintain a healthy body weight

- Aim to stay in a healthy weight range. Being overweight can be a risk factor for developing lymphoedema. If you are overweight, talk to your doctor about how to achieve a healthy weight.
- Eat a variety of nutritious food each day – aim for at least 5 serves of vegetables and 2 serves of fruit, and choose a variety of wholegrain, wholemeal and high-fibre foods, such as bread, pasta, oats, rice, legumes (beans, peas and lentils) and nuts.
- ▶ See our *Nutrition and Cancer* booklet.

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Recognising and managing infections

How an infection starts

If lymph fluid can't drain properly, bacteria can multiply and an infection may start in the affected area or sometimes more generally in the body.

Who is at risk

People with lymphoedema are at higher risk of getting a serious infection known as cellulitis.

Signs of cellulitis

Redness, painful swelling, warm skin and fever, and feeling generally unwell.

When to start treatment

See your doctor immediately, as antibiotics may be necessary. Treating symptoms early will improve management of cellulitis. Having one episode of cellulitis increases the risk of further infections.

When to take antibiotics

Talk to your doctor about an "in case" prescription for antibiotics, so you can start antibiotics as soon as you notice symptoms. If you have cellulitis several times during the year, taking antibiotics for an extended period may help.

Diagnosis

Your lymphoedema practitioner or another health professional will ask about your medical history and assess the level of swelling and any pitting, thickening or damage to the skin. The size of the affected limb will be compared to the other limb, and any differences assessed. This is done in different ways:

- using a tape measure to measure circumference
- using an electric charge (bioimpedance spectroscopy) to calculate the amount of fluid
- taking photos of more difficult to measure areas, such as the head, neck, trunk and genitals
- using a doppler ultrasound to rule out a blood clot (deep vein thrombosis)
- less commonly, using magnetic resonance imaging (MRI), computed tomography (CT) or an ultrasound to show extra fluid in tissues or tissue changes
- using infra-red imaging to show differences in skin temperature, which may be a sign of infection or the lymphatic system not working well.

Staging lymphoedema

There are several staging systems used to describe lymphoedema, and the system most commonly used in Australia was developed by the International Society of Lymphology (ISL). It divides lymphoedema into mild, moderate and severe – from no swelling to gentle pressure leaving an indent on the skin (known as pitting). In the severe stage, the skin becomes hard and more fatty.

It is important for all stages of lymphoedema to receive ongoing treatment and care.

Who will provide treatment?

Lymphoedema usually requires care from a range of health professionals including a lymphoedema practitioner, your GP, podiatrist and dietitian.

Lymphoedema practitioners – may be an occupational therapist, physiotherapist or nurse with specialist training in treating and managing lymphoedema. A lymphoedema practitioner assesses people with lymphoedema, develops treatment plans, prescribes compression garments, and provides ongoing treatment and care. They may work as part of a lymphoedema service in a public or private hospital or in private practice.

Doctors – your GP, oncologist or surgeon may diagnose the condition, coordinate your medical treatment and refer you to a trained lymphoedema practitioner. Your GP will work with you to develop a treatment plan to manage cellulitis.

How to find a lymphoedema practitioner

The Australasian Lymphology Association maintains an online national register of trained lymphoedema practitioners. Visit the website lymphoedema.org.au and click on "Find a Practitioner" to search the register for a practitioner near you.

Some public and private hospitals may assess and treat lymphoedema through physiotherapy or occupational therapy departments.

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Treatment and management

The aim of treatment is to improve the flow of lymph fluid through the affected area. This will help reduce swelling and improve the health of the swollen tissue. Reducing the swelling will lower your risk of infection, make movement easier and more comfortable, and improve your wellbeing.

A lymphoedema practitioner can develop a treatment plan for you based on the amount of swelling (the stage) and any other health conditions you may have. Mild lymphoedema is usually managed with exercise, skin care and a compression stocking or sleeve. Moderate or severe lymphoedema usually requires complex lymphoedema therapy (CLT). Less commonly you may have laser treatment, lymph taping and surgery.

Complex lymphoedema therapy (CLT)

For most people, CLT helps control the symptoms of lymphoedema. It includes a treatment phase and a maintenance phase. During the treatment phase, a lymphoedema practitioner provides a combination of regular skin care, exercises, manual lymphatic drainage (MLD), and compression bandaging. It may take a few days or up to several weeks to reduce the swelling and then you will be fitted with a compression garment. You will also be taught how to take over the management of your lymphoedema.

During the maintenance phase, you continue to look after your skin and exercise regularly. Wearing the compression garments prescribed by your practitioner will help maintain the improvements made in the treatment phase. It is recommended that you see your lymphoedema practitioner every 6–12 months for regular reviews, but this may vary depending on your circumstances.

CLT consists of the following strategies:

Skin care – It is important to keep your skin in good condition to prevent infections. See *How to reduce your risk of lymphoedema* on page 3 for tips.

Exercise – Regular physical activity such as walking and/or resistance training can reduce the severity and symptoms of lymphoedema by encouraging the lymph fluid to move around the body. It can also help you stay a healthy weight. Flexibility exercises can

help maintain your mobility. Resistance exercise can improve your strength plus reduce lymphoedema symptoms. Your lymphoedema practitioner may develop an exercise program for you.

➤ See our *Exercise for People Living with Cancer* booklet or *Arm & shoulder exercises after surgery* poster.

Massage therapy

Manual lymphatic drainage (MLD) – This is a specialised type of massage that is performed by a trained lymphoedema practitioner. Mild pressure is applied to the skin around the affected area to move fluid towards lymph nodes that are draining normally. The technique used during MLD will be different for each person depending on the location of the swelling and stage of lymphoedema.

Simple lymphatic drainage (SLD) – This is a simplified form of MLD, which your lymphoedema practitioner may teach you or a carer to do daily.

Although massage therapies are commonly part of CLT, the effect of MLD on the quality of life of people with lymphoedema is unclear. Research to prove the effectiveness of MLD and SLD is ongoing.

Help paying for treatment

Treatment for lymphoedema can be expensive. Costs for seeing practitioners and buying compression garments often add up. And you may need to take time off work for appointments or to manage infections.

There are options to help with treatment costs:

- If your GP refers you to a lymphoedema practitioner as part of a Chronic Disease Management Plan, you may be eligible for a Medicare rebate for up to five visits each year.
- Compression garment subsidy schemes are run by most state and territory governments. These schemes cover some, or all, of the cost of compression garments. For more information, visit lymphoedema.org.au.
- If you have private health insurance, check with your provider whether you are entitled to a rebate on compression garments.

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Compression therapy

Compression therapy involves applying graduated pressure to the affected area to reduce swelling, contain swelling and soften any thickened tissue.

There are different ways to apply compression. Bandages and wraps are used to stimulate the lymph fluid, remove the fluid and reduce swelling. Compression garments are used to maintain improvements. Compression can also be applied by intermittent pneumatic compression.

Compression for the treatment of lymphoedema needs to be used on an ongoing basis: if stopped, the swelling will usually return.

A compression garment needs to be fitted by a trained lymphoedema practitioner. This will ensure you have the right pressure and good pressure gradient. Using a poorly fitted compression bandage or garment can make lymphoedema worse. It may cause swelling in other parts of the body, discomfort and further damage to the lymphatic system.

Intermittent pneumatic compression (often called a pump) – This machine inflates and deflates a plastic garment placed around the affected area to stimulate lymphatic fluid. It's recommended you have MLD or SLD before using the pump.

The pump can be used at home but it's important a trained practitioner shows you how to use the pump and adjust the pressure to your needs. Depending on the type of pump used, you either sit or lie down while wearing the pump.

A compression pump may be used for people who are unable to wear a compression garment.



Compression therapy is not suitable for everyone with lymphoedema. It can be dangerous for people with a range of conditions, for example, uncontrolled congestive heart failure or uncontrolled high blood pressure. These conditions need to be under control before you start compression therapy.

Compression bandages/wraps

- applied by a trained lymphoedema practitioner
- uses inelastic (short-stretch) bandages or wraps
- changed regularly as the swelling reduces; how often they need changing will depend on the type of bandaging and how quickly the swelling reduces
- worn day and night (24 hours)

Compression garments

- self-applied (you put them on yourself)
- worn during the day as soon as possible after getting up; you may wear a lighter garment at night
- can be off-the-shelf or custom-made
- may be a stocking (leg), sleeve (arm), glove/gauntlet (hand), bra/singlet/vest (breast or chest), leotard (trunk), bike shorts with padding, or scrotal supports (genitals)
- available in different skin tones, sizes and grades of pressure
- garments must be professionally fitted to ensure the pressure and fit are correct
- handwash garment daily according to the manufacturer's instructions – this will help it last longer and maintain its compression
- you will need at least two sets: one to wear and one to wash
- replace garment regularly (every 6 months or as required); you need to remeasure for a new garment if your body weight changes or the size of the affected area changes
- may need to wear a cotton liner between the compression garment and your skin
- may need to use with additional padding material to increase or spread the local pressure
- ask your lymphoedema practitioner whether you should wear a garment during airplane travel

Tips

- Only wear a garment if recommended by your doctor or lymphoedema practitioner.
- Your lymphoedema practitioner will show you how to put on and take off the garment. They may also recommend aids and techniques to use if you find getting your garments on and off difficult.

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Avoiding pressure on the affected area

If possible, you should:

- offer an unaffected arm for blood pressure monitoring, injections and blood taking
- keep cool in summer as the heat may make swelling worse – have cold showers, stay indoors during the hottest part of the day and drink plenty of water
- wear jewellery and clothing (including underwear and bra) that fits well and doesn't put pressure on the affected area or leave marks on your skin.

Laser treatment

This treatment uses low-level laser to target cells in the lymphatic system. This may reduce the volume of lymph fluid in the affected area, any thickening of the skin and any pain. Your lymphoedema practitioner will use a handheld device or a larger scanner to apply infra-red light beams to the affected area. You will not feel any heat.

There is some evidence that laser treatment works well when used with lymphatic drainage and compression therapy. Research is still continuing to find the treatment that works best.

Lymph taping

Some early research suggests that a special tape called kinesio tape can help lymph fluid drain from the affected area to working nodes. The tape is different from strapping tape, and your lymphoedema practitioner will tell you whether this could be part of your management plan.

Surgery

Most people are able to manage lymphoedema with CLT (see page 5), but surgery may be an option when lymphoedema doesn't respond to other treatments or you are not satisfied with standard treatment. To work out whether surgery is right for you, your specialist will consider the extent of the swelling, how often you get infections, and your general health.

It is becoming common to have surgery before the lymphatic system becomes badly affected and the tissues have changed a lot. Speak to your GP or surgeon about this option.

As with all surgery, there are significant risks involved. These include scarring, nerve damage, blood clots, infection, loss of mobility, further damage to the lymphatic system, and continuing lymphoedema. Most people still need to wear a compression garment after surgery.

Examples of surgery for lymphoedema include:

Liposuction – In some people, the lymphoedema fluid changes into fatty tissue, but CLT doesn't reduce the fat. Liposuction removes fat from under the skin of the affected area but the limb will look smaller. It should only be an option when CLT cannot reduce the swelling. Liposuction can reduce swelling in the long term and the size of the affected area can be maintained when combined with compression therapy. This treatment is not a cure for lymphoedema – it's essential to continue wearing a compression garment.

Lymphatic reconstruction (anastomosis) – This uses microsurgery to repair or create a new pathway for the lymph fluid to drain out of the area. This technique appears to work better for people with early-stage lymphoedema. Further research on the long-term impact on people who have undergone this surgery is needed.

Tissue transfer – This involves transferring healthy lymph nodes from an unaffected area of the body to the affected limb. Further research is required into whether this technique is effective in the long term.

Medicines

There is no proven drug treatment for lymphoedema. Although diuretics (water pills) help remove fluid from the body when it's caused by heart or blood pressure problems, they don't work well for lymphoedema as lymph fluids are generally protein rich. Once the diuretic is stopped the fluid usually returns to the area affected by lymphoedema.

There is little evidence to support taking naturopathic medicines or supplements such as selenium to help reduce the symptoms of lymphoedema. High doses of selenium can be harmful. Talk to your doctor before taking any supplements or medicines to ensure they are not harmful and don't interact with any other medicines you are taking.

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Coping with lymphoedema

Lymphoedema can cause physical and emotional strain, so it's important to look after your wellbeing. Having lymphoedema can affect how you feel about yourself (self-esteem) in several ways, including:

- **body image** – you may be self-conscious about the swelling and how you look; or you may have trouble finding suitable clothes and footwear, which can affect how you feel about yourself
- **sexuality and intimacy** – you may lose interest in sex, or you may feel that any visible changes make you less attractive and worry others will reject you
- **depression** – the chronic nature of lymphoedema may mean you feel overwhelmed by the ongoing treatment and by the permanent reminder of having had cancer
- **social isolation** – you may avoid work and social activities because of worry about how you look or because you find it difficult to move around.

It is natural to focus on the part of your body that has changed. Give yourself time to get used to any physical changes. You may experience a wide variety of emotions, including anger, anxiety and resentment. Everyone has their own way of coping with their emotions. Some people find it helpful to talk with family and friends, while others seek professional help from a counsellor. You may find it helpful to talk with other people who are dealing with lymphoedema.

See our *Sexuality, Intimacy and Cancer* and *Emotions and Cancer* booklets. Call Cancer Council 13 11 20 to find out whether a lymphoedema support group is available in your area.

If you have continued feelings of sadness, have trouble getting up in the morning or no longer do things that previously gave you pleasure, you may be experiencing depression. Talk to your GP as counselling or medicines may help. For information about coping with depression and anxiety, call 1300 22 4636 or visit beyondblue.org.au.

References

1. National Breast and Ovarian Cancer Centre, *Review of research evidence on secondary lymphoedema: Incidence, prevention, risk factors and treatment*, NBOCC, Surry Hills, NSW, 2008.
2. Position statement, *The use of compression garments in the management of lymphoedema*, ALA National Council, 2012.
3. Lymphoedema Framework, *Best Practice for the Management of Lymphoedema*, International consensus, MEP Ltd, London, 2006.

Where to get help and information

- **Visit lymphoedema.org.au** – for information from the Australasian Lymphology Association.
- **Call Cancer Council 13 11 20** – health professionals can listen to your concerns, link you to services and support groups. You can also find information on your local website:

Cancer Council websites

| | |
|----------------|--|
| ACT..... | actcancer.org |
| NSW | cancercouncil.com.au |
| NT | nt.cancer.org.au |
| QLD | cancerqld.org.au |
| SA..... | cancersa.org.au |
| TAS | cancertas.org.au |
| VIC | cancervic.org.au |
| WA..... | cancerwa.asn.au |
| Australia..... | cancer.org.au |

Acknowledgements

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Note to reader

Always consult your doctor about matters that affect your health. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this fact sheet.



For information and support on cancer-related issues, call Cancer Council 13 11 20. This is a confidential service.