

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 we've used the term lymphoedema. Not all people treated for cancer will get lymphoedema. We hope this fact sheet will help you, your family and friends understand what lymphoedema is 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 around the body.

Lymph fluid – A clear fluid that travels from the tissues in the body, carrying nutrients and immune cells and removing bacteria and cell debris, before being emptied into the bloodstream. This fluid is rich in proteins.

Lymph nodes (glands) – Small, bean-shaped structures found along the lymph vessels. Lymph nodes are located throughout the body, including the neck, underarms, chest, abdomen and groin. The lymph nodes filter the lymph fluid as it passes through the body, removing and destroying bacteria, viruses and other harmful substances.

Lymph tissue – This includes the lymph nodes, spleen, bone marrow, thymus, tonsils and some tissues in the digestive tract.

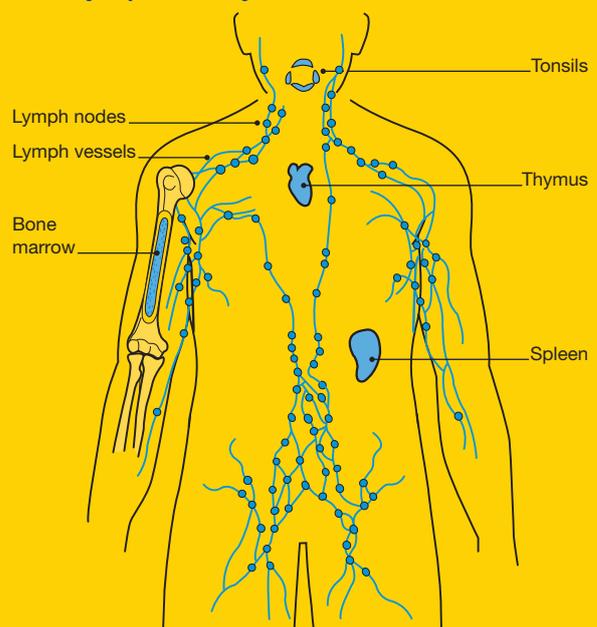
The lymph fluid, lymph nodes and lymph tissue all contain white blood cells called lymphocytes, which help protect the body against disease and infection.

What is lymphoedema?

Lymphoedema is swelling (oedema) that occurs when lymph fluid builds up in the tissues under the skin. This happens because the lymphatic system is not working as it should 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 (having an underdeveloped lymphatic system) or secondary. This fact sheet is only about secondary lymphoedema following treatment for cancer.

Secondary lymphoedema results from damage to the lymphatic system, including from cancer or cancer treatment. Sometimes lymph nodes and lymph vessels are removed or damaged during surgery or radiotherapy, 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



Understanding Lymphoedema

Swelling can be a temporary effect of surgery or radiotherapy. If it continues for more than three months, it is called secondary lymphoedema and is a chronic (long-term) condition.

Though lymphoedema may be ongoing, it can usually be well managed, particularly if diagnosed early. If left untreated, lymphoedema can cause a range of problems, including:

- scarring and thickening of the skin (fibrosis)
- discomfort and sometimes pain
- difficulty in completing your usual activities due to a reduced range of movement
- difficulty in fitting into clothes or shoes
- an increased risk of infections and of small infections becoming more serious (see box, page 3)
- lymph fluid seeping from the skin (lymphorrhoea)
- very rarely, it can lead to lymphangiosarcoma, an uncommon soft tissue cancer.

When does lymphoedema develop?

Lymphoedema can affect people at any stage: during active treatment, when cancer free or in remission, while living with advanced cancer, or during palliative treatment. Lymphoedema can also develop months or years after treatment.

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. Some people who are at risk never develop it.

Some factors increase the risk:

- certain types of cancer that affect the lymphatic system, e.g. a tumour growing near a lymph node or vessel can block the flow of lymph fluid
- surgical removal of 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
- radiotherapy that causes scarring and thickening of the lymph nodes and lymph vessels
- 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)
- being overweight or obese
- an existing problem with the lymphatic system

- certain chemotherapy drugs (talk to your oncologist if you are concerned)
- rheumatoid arthritis
- having reduced mobility.

In some hospitals, you may be able to see a lymphoedema practitioner who will assess your risk of developing lymphoedema. They may also teach you some simple exercises to do after treatment to help reduce your risk and regain movement.

Starting an exercise program early in treatment, looking after your diet and managing your weight may lower the risk of developing lymphoedema. For more information, see Cancer Council's free booklets *Exercise for People Living with Cancer* and *Nutrition and Cancer*. After surgery, it is important to take good care of your skin and keep it moisturised. It can also be helpful to massage any scar tissue.

How common is lymphoedema?

Lymphoedema can occur following treatment for many different cancers (see table below). There is little statistical evidence 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, melanoma or prostate cancers.¹

Cancer type	Affected areas
Upper limb lymphoedema	
breast	armpit, arm, hand, breast or chest
head and neck	neck, below the chin or face
melanoma	neck or arm
Lower limb lymphoedema	
bladder	genitals or legs
cervical	legs
melanoma	legs
ovarian	genitals or legs
prostate	legs, abdomen/trunk or genitals
uterine	legs
vulvar/vaginal	genitals or legs

Understanding Lymphoedema

What are the symptoms?

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 doctor soon after they appear.

Signs may begin gradually in the affected area, and they may come and go. If there is any doubt that the symptoms are an early sign of lymphoedema, ask your general practitioner (GP) to refer you to a lymphoedema practitioner for assessment.

You may have one or more of the following signs:

- tightness, heaviness or fullness
- aching or tingling feeling
- visible swelling
- not being able to fully move the affected limb
- pitting of the skin (when an indentation or mark remains in the skin after pressure is applied).

Diagnosis

Your doctor will look at your medical history and examine the affected area. They will assess the level of swelling and any pitting, thickening or damage to the skin. If the lymphoedema is in an arm or leg, your doctor will compare the size of the affected limb to the other limb, and measure any differences.

Many doctors will refer you to a trained lymphoedema practitioner for a full assessment. You may have some of the following tests:

Volume measurement – Having your limbs measured before treatment for cancer can help you determine the extent of any change after treatment. It can also help track changes to swelling over time and in response to treatment. If you have lymphoedema in an arm or leg, it will become larger (increase in volume) because of the additional

🗣️ My experience is that lymphoedema is very manageable if you notice the signs early. Although I'd had lots of lymphoedema education I actually missed the signs and didn't realise I had it until I developed cellulitis. I had noticed pitting in my skin, but didn't know this was a sign of lymphoedema. 🗣️ *Suzanne*

Identifying and managing infections

- Lymph fluid removes bacteria from tissues – if it can't drain properly, the stagnant, protein-rich fluid can become infected more easily.
- People with lymphoedema have a higher risk of getting a serious infection such as cellulitis in the affected area. Signs of cellulitis include redness, painful swelling, warm skin and fever. If you think you have an infection see your doctor immediately, as antibiotics may be necessary. Symptoms are better managed if treated early.
- Having one episode of cellulitis increases the risk of further infections. Talk to your doctor about an "in case" prescription for antibiotics, particularly if you are going away on holiday, so you can start antibiotics when you first notice the symptoms.
- If you have cellulitis several times during the year, you may benefit from taking antibiotics for an extended period.

lymph fluid trapped in the tissue. This increase in volume is usually measured with a tape measure or through bioimpedance spectroscopy.

Bioimpedance spectroscopy – This painless test uses very mild electrical signals to calculate how much fluid is in one limb compared to the other.

Photographic record – Some areas of the body (such as the head, neck, trunk and genitals) are difficult to measure. Photos may be taken, with your consent, as a way of assessing changes in swelling.

Doppler ultrasound – This test is used to rule out a blood clot (deep vein thrombosis) as the cause of your swelling.

Imaging tests – Tests such as magnetic resonance imaging (MRI), computed tomography (CT) or an ultrasound can show extra fluid in tissues or skin thickening. These tests are not commonly used to detect lymphoedema following cancer treatment.

Understanding Lymphoedema

Staging

Following a thorough physical assessment, your lymphoedema practitioner will assign a stage to the lymphoedema. This stage can be used to recommend appropriate treatment and management strategies. If left untreated, lymphoedema will continue to get worse and become more difficult to treat successfully.

Stage 0 (latent)	Stage I (mild)	Stage II (moderate)	Stage III (severe)
Circulation and drainage of lymph fluid is affected but there is no swelling.	Fluid gathers and causes mild swelling that subsides when the affected limb is elevated (raised); there may be pitting of the swollen skin (pitting is when an indentation or mark remains in the skin after pressure is applied).	Swelling does not reduce when the affected limb is elevated; pitting of the skin is present; tissues begin to harden.	There is a large amount of fluid; tissue in the affected area is hard (fibrotic); there is no pitting of the skin; the appearance of the skin changes (e.g. thickened areas, dark patches and wart-like bumps can appear).

Who will provide treatment?

Doctors – your GP, oncologist or a vascular surgeon may diagnose the condition, oversee your medical treatment and refer you to a trained lymphoedema practitioner.

Lymphoedema practitioners – may be a doctor, occupational therapist, physiotherapist or nurse with specialist training in lymphoedema management. They assess people with lymphoedema, develop treatment plans and provide ongoing care.

Lymphoedema services – these specialist centres have expert teams who manage lymphoedema on a regular basis. They can provide education and advice, assess symptoms, develop treatment plans, and prescribe compression garments. They may also provide treatment such as manual lymphatic drainage and compression bandaging.

How to find a lymphoedema practitioner

The Australasian Lymphology Association maintains a national directory of trained lymphoedema practitioners. Visit lymphoedema.org.au/the-register/find-a-practitioner to search the registry for a practitioner in your area, or talk to your doctor about a referral to a lymphoedema service. Public hospitals may assess and treat lymphoedema through physiotherapy or occupational therapy departments.

Treatment and management

Lymphoedema requires lifelong self-care and management. It is important to find a treatment that you can incorporate into your lifestyle and maintain in the long term. If you feel overburdened by your treatment schedule, talk to your lymphoedema practitioner. They may be able to suggest some changes to make it more manageable for you.

The focus 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, improve your wellbeing and make movement easier.

In the early stages of lymphoedema, treatment may focus on exercise and elevation. Some people will be advised to wear a compression stocking or sleeve. Other people with more advanced lymphoedema will require complex lymphoedema therapy.

Other ways to manage lymphoedema include manual lymphatic drainage, compression therapy, laser treatment and surgery.

It is important that you consult a lymphoedema professional who can tailor a treatment plan for you based on the location and stage of the lymphoedema and any other health conditions you may have.

Understanding Lymphoedema

Complex lymphoedema therapy (CLT)

This is the standard treatment used for chronic lymphoedema. The majority of people will respond well to CLT. It aims to reduce symptoms such as swelling, improve the condition of the skin, prevent infections and improve quality of life.

CLT consists of a treatment phase and a maintenance phase. During the treatment phase, a lymphoedema practitioner will provide a combination of regular skin care, manual lymphatic drainage (MLD), exercises and compression bandaging to reduce the swelling. This phase may last for only a few days or up to several weeks.

Once the swelling has been reduced you will enter the maintenance phase. Your lymphoedema practitioner will teach you how to care for your skin, how to perform self-massage known as simple lymphatic drainage (SLD), and how to do some suitable exercises. Wearing the compression garments prescribed by your practitioner will ensure that the gains made in the treatment phase are maintained. It is recommended that you see your lymphoedema practitioner for regular reviews every 6–12 months.

CLT components

Skin care – It is very important to care for your skin to prevent infections. You should regularly look over your skin for cuts and scratches, redness, dryness, and signs of bacterial or fungal infections. Make sure to dry your skin thoroughly after washing to help prevent fungal infections. Apply a moisturiser every day to help protect your skin – dry skin can lead to small skin tears and infections. See *How to prevent and/or manage lymphoedema* on page 7 for more tips on looking after your skin.

Manual lymphatic drainage (MLD) – This specialised type of massage is performed by a trained lymphoedema practitioner. It involves applying light pressure to the skin around the swollen area to stimulate the lymph vessels and improve the flow of lymph fluid. 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) – Your lymphoedema practitioner may teach you a simplified form of MLD, which you may be advised to do daily.

Sequential intermittent pneumatic compression

– This device applies pressure by using a compression pump to inflate and deflate a plastic garment placed around the affected area. It is given alongside MLD or SLD. The device can be used as a home treatment under the guidance of a trained professional to ensure you apply the correct amount of pressure for your situation.

Exercise – Regular physical activity such as walking can reduce the severity and symptoms of lymphoedema by encouraging the lymph fluid to move around the body. Flexibility exercises can help with maintaining your mobility. Your lymphoedema practitioner may develop a program of exercise tailored to your particular situation and abilities. For more information, see Cancer Council's *Exercise for People Living with Cancer* booklet or *Exercises after breast surgery* poster.

Compression therapy – Compression therapy involves applying pressure to the area to help control the swelling associated with lymphoedema. It can help prevent the redevelopment of lymph swelling in the affected area and soften any thickened tissue. Pressure can be applied using compression bandages or compression garments (see page 6). It can also be applied by a compression pump.

Compression is a long-term treatment: if stopped, the swelling will return. If you find it difficult to take your garments on and off, talk to your lymphoedema practitioner about what aids are available to help you. Some people find rubber gloves helpful.

If compression therapy is done incorrectly, it can cause swelling in other parts of the body, pain and further damage to the lymphatic system. It is important that you talk to your lymphoedema practitioner about appropriate therapies for you.

! Compression therapy is not suitable for all people 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 stabilised before starting compression therapy.

Understanding Lymphoedema

Compression bandages

- used to stimulate the lymph flow and remove the fluid (decongestive)
- applied by a trained lymphoedema practitioner
- uses inelastic (short-stretch) bandages that have a massaging effect
- 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

- used to keep the fluid from returning
- self-applied (you put them on yourself)
- worn during the day; you may wear lighter compression garments at night
- can be ready-to-wear or custom-made
- garments must be professionally fitted to ensure the pressure and fit is correct
- need daily washing so you will need at least two sets; one to wear and one to wash
- need to be replaced regularly (every 3–6 months)
- may be a stocking (leg), sleeve (arm), glove/gauntlet (hand), bra/singlet/vest (breast or chest), leotard (trunk), bike shorts with padding (genitals)
- may need a cotton liner between the compression garment and your skin
- may need to use with additional padding material to increase the pressure

Subsidies for compression garments

Compression garments can be expensive. For information about available subsidy schemes visit lymphoedema.org.au. If you have private health insurance, check with your provider whether you are entitled to a rebate on compression garments.

Laser treatment

Low-level laser therapy may reduce the volume of lymph fluid in the affected area, any thickening of the skin and any pain. Your lymphoedema practitioner will apply infrared light beams to the affected area using a hand-held device or a larger scanner. You will not feel any heat. There is some evidence that this therapy is effective when used alongside lymphatic drainage and compression therapy. Research is still ongoing into the most effective treatment regimen.

Surgery

Most people will be able to manage their lymphoedema with CLT (see page 5). Surgery may be an option in some cases when lymphoedema doesn't respond to other treatments. Your doctor will consider a range of factors when assessing your suitability for surgery, including the extent of the swelling, how often you get infections and your general health.

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. People having any of the following procedures will still need to wear compression garments after surgery.

Liposuction – This involves the removal of fat from under the skin of the affected area. It should only be undertaken when CLT cannot reduce the swelling. Liposuction can reduce swelling in the long term when combined with compression therapy after surgery.

Lymphatic reconstruction (anastomosis) – This involves microsurgery to repair or create new lymphatic pathways to drain the fluid. This technique appears to be more effective in the early stages of lymphoedema, but additional research is needed into the effectiveness of this treatment.

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 help remove fluid from the body, they do not remove lymph fluid and can cause dehydration. Your doctor may prescribe you diuretics for other conditions such as high blood pressure, but they are not recommended for 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 about any supplements or medicines to ensure they don't interact with any other medicines you are taking and are not harmful.

Understanding Lymphoedema

How to prevent and/or manage lymphoedema

Self-care is an important aspect of lymphoedema prevention and management. Know the signs and symptoms of lymphoedema. If you notice changes in the affected part of your body, talk to your doctor. There are many steps you can take to reduce the risk of developing lymphoedema or to stop it progressing.

Care for your skin	Exercise/daily activities	Compression garments
<ul style="list-style-type: none"> • Keep your skin healthy and unbroken to reduce the risk of infection. • Use a pH neutral soap when washing your skin, avoid scented products and moisturise daily to prevent dry, irritated skin. Dry skin is more prone to tearing and breaking. • Don't pick or bite your nails, and don't cut your cuticles with scissors. Use cuticle moisturiser to help avoid your cuticles splitting. • Always wear gloves and shoes for gardening, housework and outdoor work to protect your skin. • Take care to protect your skin from cuts or burns when cooking. • Protect your skin from the sun with clothing, a broad-brimmed hat, sunglasses and sunscreen. • Apply insect repellent to prevent insect bites, which can swell and become infected. • Avoid scratches from pets and thorns; take care when shaving to avoid cuts; and protect your fingers from needle pricks when sewing. • If you damage your skin, treat it promptly – clean the wound and cover it with a clean dressing. • Talk to your doctor about how to best manage any eczema, dermatitis or other skin conditions in the affected area. • Avoid tinea by washing and drying well between the toes. If tinea is present, use antifungal treatments for several weeks. • Seek medical help urgently if you think you may have an infection. 	<ul style="list-style-type: none"> • Maintain a healthy body weight. If overweight, talk to your doctor about how to achieve a healthy weight range. • Do regular exercise to help the lymph flow. Find something you enjoy – this may be swimming, yoga, bike riding, aquarobics, walking, running, or attending the gym. • If lifting weights, increase the weight and intensity gradually. Be guided by how your limb responds. • Use the affected limb normally to improve the lymph flow. • For lower limb lymphoedema, avoid standing for long periods or crossing your legs. If your job requires you to be seated, try to move around and change position frequently. • For upper limb lymphoedema, avoid carrying heavy objects with the affected arm/hand if you are not used to doing so. Continue your usual lifting, such as washing or shopping, but avoid one-off heavy lifting, such as moving heavy boxes or furniture, as it may worsen your symptoms. • If you have lymphoedema in your arm, the unaffected arm is preferred for blood pressure monitoring, injections and blood taking. • Avoid wearing jewellery or clothing that constricts the affected area or leaves marks in your skin. • Avoid extremes of temperature, either hot or cold. Swelling may be worse in summer due to the heat: stay indoors during the hottest part of the day and drink plenty of water. 	<ul style="list-style-type: none"> • Only wear a garment if recommended by your doctor or lymphoedema practitioner. • Ensure any garment you wear is fitted by a trained lymphoedema practitioner. • Your lymphoedema practitioner will show you how to put on and take off the garment. They may also talk to you about aids you can use if you find it difficult getting your garments on or off. • If you are at risk of developing lymphoedema, talk to your doctor or lymphoedema practitioner about wearing a compression sleeve during air travel. Long periods of physical inactivity with reduced cabin pressure may increase the strain on the lymphatic system. • See table on page 6 for more information about compression garments.

Understanding Lymphoedema

Effect on your emotional wellbeing

Having lymphoedema can affect how you feel about yourself in a range of 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 impact on how you feel about your appearance
- **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 can be overwhelming; you may feel burdened by the ongoing nature of treatment and by the permanent reminder of having had cancer
- **social isolation** – you may avoid work and social activities because of anxiety 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. Intimacy is expressed in different ways and most people need some kind of physical connection to others. If you feel uncomfortable about a part of your body, remember that sexual attraction is not based on a single body part. See Cancer Council's *Sexuality, Intimacy and Cancer* booklet for more information.

It is normal to 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. Call Cancer Council 13 11 20 to find out what support services and groups are 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. The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to beyondblue.org.au or call their support service on 1300 22 4636.

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. Lymphoedema Framework, *Best Practice for the Management of Lymphoedema*, International consensus, MEP Ltd, London, 2006.

Where to get help and information

- **Call Cancer Council 13 11 20** – for more information about lymphoedema. Trained health professionals can listen to your concerns, provide additional information, and put you in touch with local services and support groups. Ask for free copies of booklets that may be relevant to you, or download digital versions from your local Cancer Council website.
- **Australasian Lymphology Association** – lymphoedema.org.au.

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

This information is based on best practice guidelines⁹ for lymphoedema and has been developed with help from a range of health professionals and people affected by lymphoedema. It was reviewed by: Dr Helen Mackie, Rehabilitation Physician, Macquarie University Lymphoedema Clinic, NSW; Gemma Arnold, Lymphoedema Service Coordinator and Senior Clinician, Physiotherapy Department, Lymphoedema Clinic, Calvary Public Hospital Bruce, ACT; Brenda Clasquin, 13 11 20 Consultant, Cancer Council NSW; Suzanne Elliott, Consumer; Jenny Pope, Physiotherapist and Lymphoedema Practitioner, Eastern Hills Lymphoedema Practice, WA; Chris Rivett, Oncology Clinical Nurse and Breast Care Nurse, Western Hospital, SA.

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.