



# Understanding Melanoma

A guide for people with cancer,  
their families and friends

A blue circular callout containing the text "Cancer information". A thin orange line extends from the bottom of the circle, curving to the left and ending in a telephone handset icon.

Cancer  
information

For information & support, call

**13 11 20**

## Understanding Melanoma

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*Understanding Melanoma* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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This booklet is funded through the generosity of the people of Australia.

### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. 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 booklet.

### Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



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# Introduction

This booklet has been prepared to help you understand more about skin melanoma.

Many people feel shocked and upset when told they have melanoma. We hope this booklet will help you, your family and friends understand how melanoma is diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet to your family and friends for their information.

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by melanoma. It is based on clinical practice guidelines.<sup>1,2</sup>

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer  
Council  
13 11 20**

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# What is cancer?

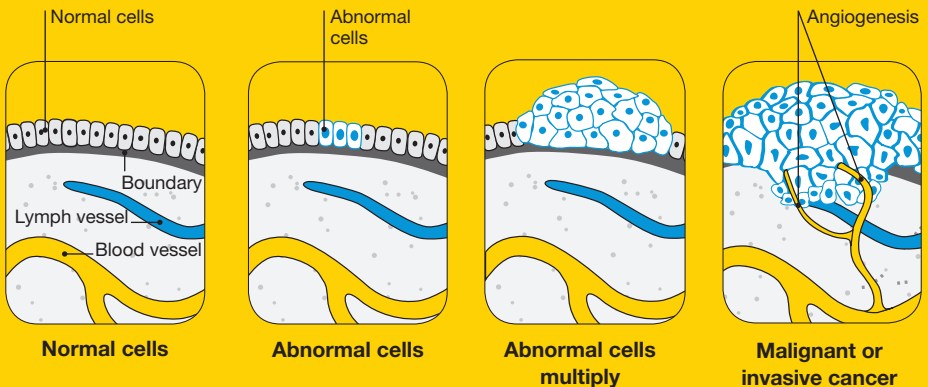
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which sometimes also have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

## How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels in a process called angiogenesis.

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, melanoma that has spread to the bones is called metastatic melanoma, even though the person may be experiencing symptoms caused by problems in the bones.

## How cancer spreads

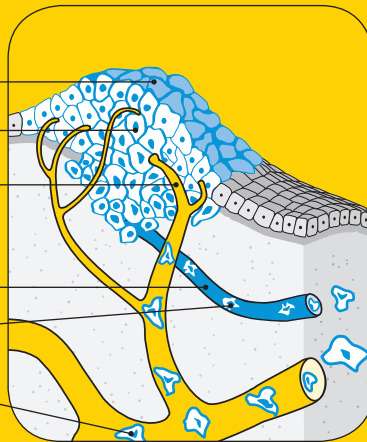
Primary cancer

Local invasion

Angiogenesis –  
tumours grow their  
own blood vessels

Lymph vessel

Metastasis –  
cells invade other  
parts of the body via  
blood vessels and  
lymph vessels





# The skin

The skin is the largest organ in the body. It acts as a barrier to protect the body from injury, control body temperature and prevent loss of body fluids. Skin, like all other body tissues, is made up of cells. The two main layers of the skin are the epidermis and the dermis. Below these is a layer of fatty tissue (subcutis).

The epidermis is the top, outer layer of the skin. It contains three main kinds of cells:

**Squamous cells** – These flat cells are packed tightly together to make up the top layer of skin and form the thickest layer of the epidermis. These cells eventually die and become the surface of your skin. Over time our body sheds these dead skin cells.

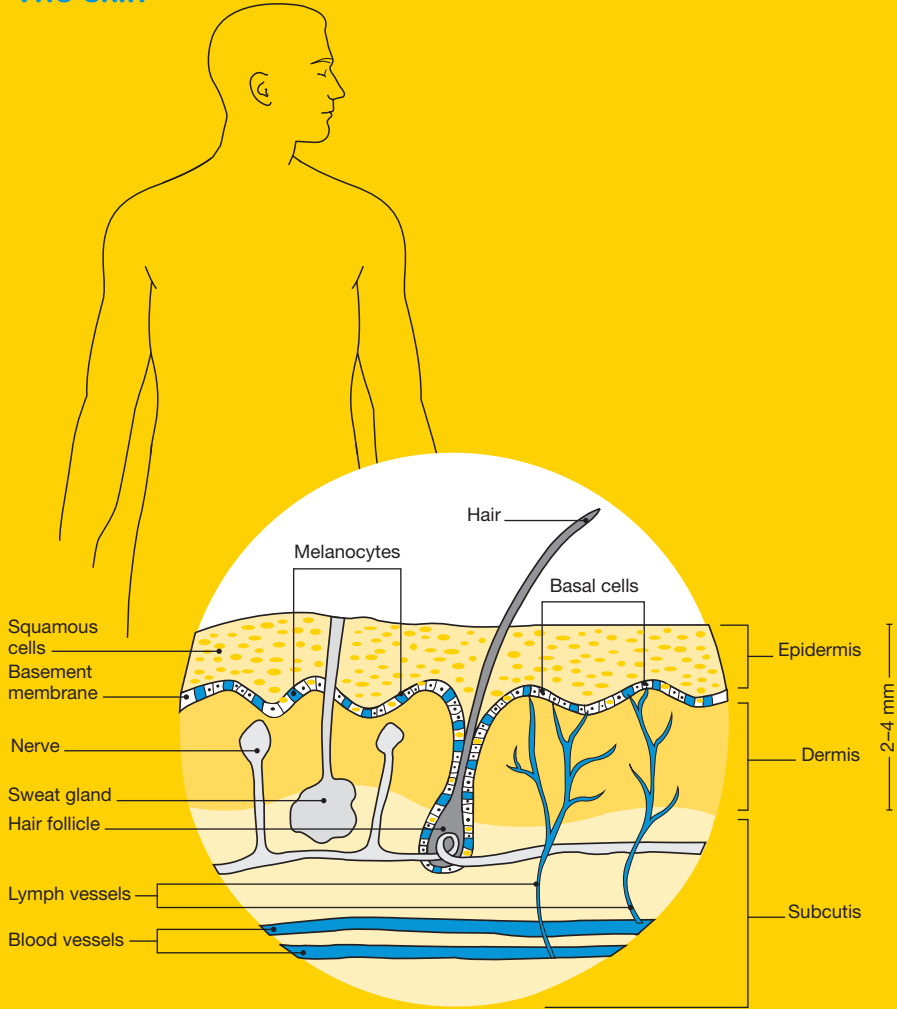
**Basal cells** – These block-like cells make up the lower layer of the epidermis and multiply constantly. As they age, they move upwards in the epidermis and flatten out to form squamous cells.

**Melanocytes** – These cells sit between the basal cells of the skin and produce a dark pigment called melanin, the substance that gives skin its colour. When skin is exposed to ultraviolet (UV) radiation, melanocytes make extra melanin to try to protect the skin from getting burnt. This is what causes skin to tan. Melanocytes are also in non-cancerous (benign) spots on the skin called moles or naevi. Most moles are brown, tan or pink in colour and round in shape.

The dermis is the layer of skin underneath the epidermis. It is made up of fibrous tissue and contains hair follicles, sweat glands, blood vessels, lymph vessels and nerves.



# The skin





## Key questions

### Q: What is melanoma?

**A:** Melanoma is a type of skin cancer. It develops in the melanocytes (pigment cells) and usually occurs on parts of the body that have been overexposed to the sun. Rare melanomas can also start in a part of the skin or body that has never been exposed to the sun, such as the nervous system, eye and mucous membrane (lining of the mouth and digestive tract), soles of the feet, palms, and under the nails.

Although one of the less common types of skin cancer, melanoma is considered the most serious type of skin cancer because it is more likely to spread to other parts of the body, especially if not detected early. The earlier melanoma is found, the more successful treatment is likely to be.

### Q: What types are there?

**A:** The major subtypes of skin (cutaneous) melanoma are:

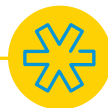
**Superficial spreading melanoma** – This is the most common type of melanoma, making up 55–60% of all cases. It is more common in younger people and is often related to a pattern of irregular high sun exposure, including episodes of sunburn. It can start as a new brown or black spot that spreads within the outer layer of the skin (epidermis), or an existing spot, freckle or mole that changes size, colour or shape. It can develop on any part of the body. This type of melanoma often grows slowly and becomes more dangerous when it invades the lower layer of the skin (dermis).

**Nodular melanoma** – This type makes up about 10–15% of melanomas. It usually appears as a round, raised lump on the surface of the skin that is often red, pink, brown or black and feels firm to touch. It may develop a crusty surface that bleeds easily. It is most commonly found in older people on severely sun-damaged skin on the head and neck. It is a fast-growing and aggressive form of melanoma, spreading quickly into the lower layer of the skin (dermis).

**Lentigo maligna melanoma** – This type of melanoma is most common in older people. It makes up about 10–15% of melanomas and begins as a large freckle (lentigo maligna) in an area of sun-damaged skin, such as the face, ears, neck and head. It may grow slowly and superficially over many years before it penetrates more deeply into the skin.

**Acral lentiginous melanoma** – This is an uncommon type of melanoma (around 1–2% of all cases). It is most commonly found on the hairless skin on the soles of the feet or palms of the hands, or under the fingernails or toenails. It commonly appears as a colourless or lightly pigmented area, which can be mistaken for a stain or bruise. In the nails, it

This booklet is about melanoma. For information about non-melanoma skin cancers (basal cell or squamous cell carcinomas), call Cancer Council **13 11 20** for a free copy of *Understanding Skin Cancer*, or download a copy from your local Cancer Council website.



most often presents as a long streak of pigment in the nail or discolouration in the skin around the nail. It may grow slowly before it becomes invasive.

**Desmoplastic melanoma** – This is another uncommon type of melanoma (around 1–2% of cases) that presents as a firm, progressively growing lump, often on the head or neck. Many are skin-coloured and not pigmented, and can be difficult to diagnose.

There are some other rarer types of non-skin melanoma. Mucosal melanomas start in the tissues in the mouth, nervous system, anus, urethra, vagina, and nasal passages. Ocular melanomas start in the eye. To find out more, call Cancer Council 13 11 20.

## **Q: How common is melanoma?**

**A:** Australia and New Zealand have the highest rates of melanoma in the world. More than 12,000 people are diagnosed with melanoma in Australia every year, accounting for 10% of all cancer diagnoses.<sup>3</sup>

Melanoma is the third most common cancer in both men and women (excluding non-melanoma skin cancers). One in 14 men and 1 in 24 women will be diagnosed with melanoma before age 85. Although melanoma is more common in people aged over 60, it is among the five most commonly diagnosed cancers in all age groups.<sup>4</sup>

## Q: What are the signs and symptoms?

**A:** Melanoma can vary greatly in the way it looks. In people who have lots of moles, melanomas stand out and look different from the other moles (known as the ‘ugly duckling’). The first sign is usually a new spot or a change in an existing mole:

- **size** – the spot may appear or begin to grow larger
- **colour** – the mole may become increasingly blotchy with different depth and shades of colour (brown, black, blue, red, white, light grey, pink or skin-coloured)
- **shape or border** – the spot may increase in height, become scaly, have an irregular edge (scalloped or notched) or lack symmetry (the halves look different)
- **itching or bleeding** – the mole may itch or bleed at times
- **elevation** – the spot may start as a raised nodule or develop a raised area, which is often reddish or reddish brown.

It is normal for new moles to appear and change during childhood and teenage years, and during pregnancy. However, all adults who develop a new mole should see their doctor to get it examined, particularly if it is noticeably different from your other moles or is raised, firm and growing. Even if you have had a mole checked before and it was benign, it is important to monitor your skin as the mole could change in the future. Talk to your doctor immediately about any changes.

Examining your skin every three months, or as recommended by your GP, will help you notice any new or changing spots.



## Q: What are the risk factors?

**A:** The main risk factor associated with all types of skin cancers is overexposure to UV radiation from the sun or another source, such as solariums (tanning beds). Solariums are now banned in Australia for commercial use because research shows that people who use a solarium have a significantly greater risk of developing melanoma.<sup>5</sup> When your unprotected skin is exposed to UV radiation, the structure and behaviour of the cells can change.

Anyone can develop melanoma. However, the risk is higher in people who have:

- unprotected exposure to the sun
- a history of childhood tanning and sunburn
- lots of moles (naevi) (more than 10 moles on the arms and more than 100 on the body)
- moles with an irregular shape and uneven colour (dysplastic naevi)
- a previous melanoma or other type of skin cancer
- a strong family history of melanoma
- pale, fair or freckled skin, especially if it burns easily and doesn't tan
- experienced short, intense periods of exposure to UV radiation, such as on weekends and holidays, especially if it caused sunburn
- light-coloured eyes (blue or green), and fair or red hair
- a weakened immune system (which could be caused by having undergone immune suppression or taking certain medicines after an organ transplant).

Overexposure to UV radiation can permanently damage the skin. This damage adds up over time. Even though sun protection during childhood is very important, increased protection against sun exposure will help prevent melanoma at any age. See pages 44–45 for information on protecting your skin from overexposure to the sun and sun damage.

## Family history of melanoma

Sometimes melanoma runs in families. For most people this is due to having a similar skin type or a similar pattern of sun exposure in childhood. Only 1–2% of melanomas in Australia involve an inherited faulty gene. Some of these genes have been identified.

The signs that melanoma could be due to an inherited faulty gene include:

- having two or more close relatives (parent, sibling or child) who have been diagnosed with melanoma
- being diagnosed with more than one melanoma on different areas of the skin

- being diagnosed with melanoma before the age of 40.

People with a strong family history of melanoma should protect and monitor their own skin, and have a professional skin check by a doctor every year from their early twenties. New moles after this age should be investigated.

If you are concerned about your family risk factors, talk to your doctor about having regular skin checks or ask for a referral to a family cancer clinic. To find out more call Cancer Council **13 11 20**.



# Diagnosis

## Physical examination

If you notice any changes to your skin, your doctor will examine you, paying particular attention to any spots you have identified as changed or suspicious. The doctor will ask if you or your family have a history of melanoma. The doctor may assess the spot using the 'ABCDE' criteria:

- **Asymmetry** – are the halves of each mole different?
- **Border** – are the edges irregular, scalloped or notched?
- **Colour** – are there differing shades and colour patches?
- **Diameter** – is the spot greater than 6 mm across?
- **Evolving** – has the spot changed over time (size, shape, surface, colour, bleeding, itching)?

Some melanomas don't follow the 'ABCDE' criteria, so your doctor may also assess whether the spot is elevated, firm or growing. Your doctor may use a handheld magnifying instrument called a dermascope to see the spot more clearly.

## Removing the mole (excision biopsy)

If the doctor suspects that a spot on your skin may be melanoma, the usual procedure is to remove the whole spot (excision biopsy) for examination by a tissue specialist (pathologist). This is generally a simple procedure in your doctor's office. Your GP may do it, or you may be referred to a dermatologist or surgeon.

You will have an injection of local anaesthetic to numb the area. The doctor will use a scalpel to remove the spot and a narrow margin (2 mm) of healthy tissue around it. The wound will usually



be closed with stitches. It is recommended that the entire mole is removed rather than a small sample. This helps ensure an accurate diagnosis and accurate staging of any melanoma found.

A pathologist will examine the tissue under a microscope to determine if it contains melanoma cells. Results are usually ready in about a week, and a follow-up appointment may be arranged to check the wound and remove your stitches. If the mole contains cancerous cells you may need further surgery, such as a wide local excision (see pages 25–26).

## Checking the lymph nodes

Lymph nodes are part of your body's lymphatic system, which removes excess fluid from tissues, absorbs fatty acids, transports fat, and produces immune cells. There are large groups of lymph nodes in the neck, armpits and groin. Sometimes melanoma can travel through the lymph vessels to other parts of the body.

Your doctor may feel the lymph nodes near the melanoma to see if they are enlarged. This may indicate the cancer has spread to the lymph nodes. To test whether the melanoma has spread, your doctor may recommend that you have a fine needle aspiration biopsy or a sentinel lymph node biopsy.

**Fine needle aspiration biopsy** – The doctor takes a sample of cells by inserting a thin needle into a suspicious lymph node. Ultrasound is often used to guide the needle to the correct node. The sample is then examined under a microscope to see if it contains cancer cells.

**Sentinel lymph node biopsy** – You will have an injection of a small amount of radioactive substance into the area where the melanoma was removed. The lymph node that absorbs the injected fluid first is the sentinel lymph node.

If the cancer has spread, the sentinel node is the most likely node to have cancer within it. The surgeon will remove this node to check for cancer cells and determine whether it's necessary to remove more lymph nodes. The removal of the sentinel lymph node is usually done under a general anaesthetic at the same time as the wide local excision (see pages 25–26). Your doctor will talk to you about this type of biopsy, and the associated risks and benefits.

If cancer cells are found in the sentinel lymph node, the remaining nodes in the area may also be removed (see page 28). This is to treat the cancer locally to try to stop the melanoma coming back in the same area or spreading from the primary site.

The risk of having melanoma in the lymph nodes increases with the thickness of the melanoma and is very low for thin melanomas. For this reason, sentinel node biopsy will usually only be offered to people if the Breslow thickness (see box opposite) of their melanoma is over 1 mm.

A sentinel lymph node biopsy can provide information that helps predict the risk of melanoma spreading to other parts of the body. This can help your doctor plan your treatment. It may also allow you to access new clinical trials (see page 24).

## Pathology report

If you have melanoma, the pathologist's report will provide your treatment team with information to help plan treatment and determine your prognosis. The following factors may be included:

**Breslow thickness** – This is a measure of the thickness of the tumour in millimetres from the epidermis to its deepest point in the skin. The thicker a melanoma, the more likely it will recur or spread to other parts of the body.

Melanomas are classified as:

- in situ – found only in the outer layer of the skin
- thin – less than 1 mm
- intermediate – 1–4 mm
- thick – greater than 4 mm.

**Clark level** – This describes how many layers of skin the cancer has gone through. It is rated 1–5, with 1 the shallowest and 5 the deepest. Breslow thickness is more important than Clark level in assigning a stage to a melanoma.

**Margins** – This is the area of normal skin around the

melanoma. If there is no tumour touching the margins, the pathologist will often describe how close the lesion came to the edge.

**Mitotic rate** – Mitosis is the process by which one cell divides into two. The pathologist counts the number of actively dividing cells (mitoses) to calculate the average number of mitoses per square millimetre.

**Ulceration** – The breakdown or loss of the outer layer of skin over the tumour is a sign of rapid tumour growth. The pathologist will determine whether ulceration is present.

**Regression** – The report will note any lymphocytes (immune cells) within the melanoma and any evidence of tumour regression (destruction).

## Staging the melanoma

The test results will help your doctors assign a stage to describe the melanoma. You may also undergo some other diagnostic tests, including blood tests and imaging tests (ultrasound, CT scan or PET scan), to assess whether the melanoma has spread from the original site to other parts of the body. Staging the melanoma helps your health care team decide what treatment is best for you.

### Staging melanoma

<b>Stage 0</b>	The melanoma is confined to the outer layer of the skin (also known as in situ melanoma).
<b>Stage 1</b>	The melanoma has not moved beyond the primary site and is 2 mm or less in thickness (may or may not have ulceration).
<b>Stage 2</b>	The melanoma has not moved beyond the primary site and is 2 mm or greater in thickness (may or may not have ulceration).
<b>Stage 3</b>	The melanoma has spread to lymph nodes near the primary site, to nearby skin or to tissues under the skin (subcutaneous).
<b>Stage 4</b>	The melanoma has spread to distant lymph nodes and/or other parts of the body such as the lungs, liver, brain or bone.

## Gene mutation testing

Approximately 40% of people with melanoma have a mutation in the BRAF gene and approximately 15% have a mutation in the NRAS gene. These mutations can cause cancer cells to multiply and contribute to the growth of melanomas. If the melanoma is advanced (metastatic), mutation testing of tissue samples is recommended to identify particular genetic mutations that may respond to some medicines. See *Targeted therapy* on page 35 for more details.

## Prognosis

Prognosis means the predicted outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease. Instead, your doctor can give you an idea about common issues that affect people with melanoma.

Melanoma can be treated most effectively in its early stages when it is still confined to the top layer of the skin (epidermis). The deeper a melanoma penetrates into the lower layers of the skin (dermis), the greater the risk that it could spread to nearby lymph nodes or other organs. In recent years, clinical breakthroughs have led to new treatments that continue to improve the prognosis for people with advanced melanoma.

## Which health professionals will I see?

Your GP will probably arrange the first tests to assess your symptoms. If these tests do not rule out melanoma, you will usually be referred to a specialist, such as a dermatologist or surgeon, who will arrange further tests and advise you about treatment options.

You may also be cared for by a range of health professionals who specialise in different aspects of your treatment, especially if you have a melanoma with a Breslow thickness greater than 1 mm, or if the melanoma has spread. This is often referred to as a multidisciplinary team (MDT). This team may include some or all of the health professionals described in the table on the next page.

<b>Health professional</b>	<b>Role</b>
<b>GP (general practitioner)</b>	assists with treatment decisions and works with your specialists to provide ongoing care
<b>dermatologist*</b>	specialises in the prevention, diagnosis and treatment of skin conditions, including melanoma
<b>general surgeon*</b>	performs surgery to remove the melanoma; skin reconstruction; and surgery on the lymph nodes
<b>reconstructive (plastic) surgeon*</b>	specialises in complex skin reconstruction techniques
<b>surgical oncologist*</b>	specialist cancer surgeon; removes melanomas and conducts more complex surgery on the lymph nodes and other organs
<b>medical oncologist*</b>	specialises in treating cancer with drug therapies such as targeted therapy and immunotherapy
<b>radiation oncologist*</b>	prescribes and coordinates the course of radiotherapy
<b>specialist nurse</b>	administers treatment and provides care and support throughout your treatment
<b>cancer nurse coordinator</b>	coordinates your care, liaises with other members of the MDT and supports your family
<b>lymphoedema practitioner</b>	educates people about lymphoedema management and provides treatment
<b>counsellor, social worker, psychologist</b>	link you to support services, provide emotional support and help manage anxiety and depression
<b>physiotherapist, occupational therapist</b>	assist with physical and practical problems
<b>palliative care team</b>	specialise in pain and symptom control to maximise wellbeing and improve quality of life

*\* Specialist doctor*

## Melanoma units

Some people, particularly if they have a deeper, invasive melanoma, are treated in specialist melanoma units located at hospitals in major cities around Australia. At these centres, specialists in melanoma work together to assess your case and recommend the best treatment.

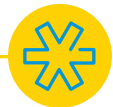
If you are referred to a melanoma unit or a multidisciplinary team by your GP, you will be able to talk to one or more medical specialists who will answer your questions, and advise you and your GP about your treatment options. The best treatment pathway will depend on the pathology and imaging results.

As well as providing treatment advice, melanoma units are also involved in research studies and may invite you to participate. They may also seek your permission to collect information and tissue and blood samples from you, for use in melanoma research.

People who are at high risk of melanoma are also often asked to take part in research studies, even if they have not been diagnosed with melanoma. See page 24 for more information on clinical trials.

To find out where a specialist melanoma unit is located, ask your doctor or call Cancer Council 13 11 20.

Most people with melanoma will only require surgery. They will not need to see a medical or radiation oncologist.





## Key points

- A melanoma diagnosis starts with an examination of the suspicious spot or mole, and any other moles on your body.
- A GP, dermatologist or surgeon can give you a local anaesthetic and remove a spot on your skin for examination by a pathologist. This is called an excision biopsy.
- The biopsy will provide information about the thickness of the melanoma (Breslow thickness) and how deeply into the skin the cancer cells have grown.
- Your doctor will feel the nearby lymph nodes to work out if the melanoma has spread to other parts of the body. If necessary, you will have a sentinel lymph node biopsy or fine needle aspiration biopsy to check the lymph nodes for cancer cells.
- Your doctor will assign a stage to the melanoma based on the test results. This describes the size of the melanoma and whether it has spread.
- Mutation testing of tissue samples is recommended only in cases of advanced (metastatic) melanoma.
- Your doctor may talk to you about possible treatments and the expected outcome of the disease (prognosis).
- There are many health professionals who care for people with melanoma.
- Some health professionals, such as medical oncologists and radiation oncologists, care for people with a melanoma that is at risk of spreading or has spread (metastatic melanoma).
- Some people visit specialist melanoma units, which are based in hospitals in major cities around Australia.





# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

## Talking with doctors

When your doctor first tells you that you have a melanoma, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 51 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

## Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research* or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).



# Treatment for early melanoma

Melanoma that is found early (stages 0–2 or localised melanoma) can generally be treated successfully with surgery. Tests such as CT or PET scans are not usually recommended for early melanoma. If the melanoma has spread to nearby lymph nodes or tissues (stage 3 or regional melanoma), treatment may also include removal of the lymph nodes and adjuvant treatments.

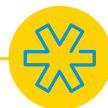
## Surgery

Surgery is the main treatment for early stage (localised) melanoma. Most of the time this is the only treatment needed.

### Wide local excision

A doctor or surgeon will do a procedure called wide local excision (removal). This means that the area where the melanoma is, as well as a small amount of surrounding normal-looking skin, will be cut out. This is called a wider or safety margin. Removing more tissue around the melanoma than was cut out during the excision biopsy reduces the risk of it coming back (recurring) locally. The safety margin is usually between 5 mm and 1 cm, depending on the type, thickness and site of the melanoma. For thicker tumours, a wider margin of up to 2 cm may be advised.

A pathologist will check the tissue around the melanoma for cancer cells. If the sample doesn't have any cancer cells, it is called a clear margin. If the margins aren't clear, you may need further surgery to remove wider margins, or other treatments (see pages 33–37).



A wide local excision is often performed as a day procedure using local anaesthetic. This means you can go home soon after the surgery, provided there are no complications. People with a melanoma thicker than 1 mm will often have a sentinel node biopsy (see page 16) at the same time and will be given a general anaesthetic. The sentinel node biopsy may be less accurate if it is performed after the wide local excision has been done.

## Repairing the wound

Most people will be able to have the surgical wound drawn together with stitches. When large skin cancers are removed, the wound may be too big to close with stitches. The surgeon may cover it using some skin from another part of your body. This can be done in two ways:

- **Skin flap** – nearby skin and fatty tissue are moved over the wound and stitched.
- **Skin graft** – a layer of skin is taken from another part of your body and placed over the area where the melanoma was removed.

The decision about whether to do a skin graft or flap will depend on many factors, such as where the melanoma is, how much tissue has been removed and your general health.

In either case, the wound will be covered with a dressing and left for several days. It will then be checked to see if it is healing properly. You will also have dressings on any area that had skin removed for a graft.

## Recovering from surgery

You may be uncomfortable for a few days after a wide local excision. Your doctor will prescribe painkillers if necessary. If you have a skin graft, the area on which the skin is grafted may look red and raw immediately after the operation. Eventually this area will heal and the redness will fade.

Your medical team will tell you how to keep the wound clean to prevent it from becoming infected. Occasionally, the original skin flap or graft doesn't take and a new one is required.

Your total recovery time will vary depending on the thickness of the melanoma and the extent of the surgery required. Most people recover in a week or two. Your doctor can also give you information about any bleeding, bruising, scarring or numbness you may have after surgery.

For more information about surgery, call Cancer Council 13 11 20 and request a free copy of *Understanding Surgery*, or download a digital version from your local Cancer Council website.

“ I went to a doctor who specialises in facial and cosmetic surgery. He said it was important to get the melanoma out straightaway. He cut out a larger piece – about the size of a 20-cent coin – and it had clear margins. The cuts from surgery were able to heal into the folds and wrinkles of my face, so the scar is not noticeable. ” John

## Removing the lymph nodes

If the sentinel lymph node biopsy (see page 16) showed that the melanoma has spread to your lymph nodes (regional melanoma), they will be removed in an operation called a lymph node dissection or lymphadenectomy. This is performed under a general anaesthetic and requires a stay in hospital. The lymph nodes you have removed are likely to be near the location of the primary melanoma. There are large groups of lymph nodes in the neck, armpits and groin.

### Side effects

Like most treatments, having your lymph nodes removed can cause side effects, such as:

- **Wound pain** – Most people will have some pain after the operation. This usually improves as the wound heals. For some people, however, pain may continue after the wound has healed, especially if lymph nodes were removed from the neck. Talk to your medical team about how to manage your pain.
- **Neck/shoulder/hip stiffness and pain** – These are the most common problems if lymph nodes in your neck, armpit or groin were removed. You may find that you cannot move the affected area as freely as you could before the surgery. It may help to see a physiotherapist.
- **Seroma/lymphocele** – This is a collection of fluid in the area where the lymph glands have been removed. It is a common side effect of lymph node surgery. Sometimes this fluid needs to be drained by having a needle inserted into the fluid-filled cavity.

## Lymphoedema

If lymph nodes have been surgically removed, swelling of the neck, arm or leg is the most common problem that can occur. Occasionally it can affect the breast tissues. This is called lymphoedema and it happens due to a build-up of lymph fluid in the affected part of the body.

The likelihood of lymphoedema following treatment depends on the extent of the surgery and whether you've had radiotherapy that has damaged your lymph nodes. It can develop a few weeks, or even several years, after treatment. Although lymphoedema may be permanent, it can usually be managed.

### How to prevent and/or manage lymphoedema

- Keep the skin healthy and unbroken. This will reduce the risk of infection.
- Wear a professionally fitted compression garment if recommended by a physiotherapist or occupational therapist.
- Always wear gloves for gardening, outdoor work and housework.
- Moisturise your skin daily to prevent dry, irritated skin.
- Use sunscreen to protect your skin from sunburn.
- Don't pick or bite your nails, or push back your cuticles.
- Avoid scratches from pets, insect bites, thorns, or pricking your fingers.
- Do light exercise to help the lymph flow, such as swimming, bike riding or light weights.
- Massage the affected area to help move fluid.
- See a lymphoedema practitioner – talk to your doctor or visit Australasian Lymphology Association, [lymphoedema.org.au](http://lymphoedema.org.au).
- Seek medical help urgently if you think you may have an infection.



## Sam's story

I have always had a lot of freckles and noticed that one on my calf had changed – it was bleeding, itching, and had become darker. Although I asked my friends “What do you think this is?” I put off doing anything about it for a few weeks.

As I live in a country town, I had some difficulty getting an appointment with a local skin specialist, so made an appointment to see him in Sydney. He removed the suspicious spot the same day.

I was really shocked and scared when the specialist called to say it was a melanoma. I was only 23 and I had no idea what would happen next.

The surgeon I was referred to found that the cancer had spread to my lymph nodes, and I had all the lymph nodes in my left leg removed. A month after the lymph nodes were removed I felt very unwell and had a rash.

I didn't know what was wrong and ended up hospitalised with an attack of cellulitis in my leg. I had a second attack of cellulitis shortly afterwards. After my surgery I participated in a clinical trial. I still have to deal with mild lymphoedema and some scarring from the surgery, and have regular check-ups with my doctor.

Connecting with others through social media really helped me deal with my feelings of isolation. It was difficult being treated in Sydney away from home, but sharing my story with others helped me to open up doors and build relationships.

I found the whole experience very overwhelming, but now have a new appreciation for life. I place a lot of importance on healthy eating, being active and staying out of the sun. I'm more aware of my own body and the need to get any changes checked out straightaway.



## Adjuvant therapies

If there's a risk that the melanoma could come back (recur), other treatments are sometimes used after surgery to try to reduce that risk. These are known as adjuvant (or additional) therapies. They may include:

- **radiotherapy** – the use of x-rays to damage or kill cancer cells (also known as radiation therapy)
- **targeted therapy** – the use of drugs to attack particular gene mutations that allow cancers to grow and spread
- **immunotherapy** – the use of drugs to stimulate the body's immune system to recognise and fight some types of cancer cells.

For further information about radiotherapy, targeted therapy and immunotherapy, see the *Treatment for advanced melanoma* chapter on pages 33–38.

You may also be offered an opportunity to participate in a clinical trial (see page 24).



## Key points

- Melanoma can be treated successfully if it is diagnosed early. This is called early stage or localised melanoma.
- Most people will only need to have the melanoma surgically removed. This usually does not require a hospital stay or further treatment.
- Treatment is based on how far the melanoma has spread.
- Melanoma is always surgically removed in a procedure called a wide local excision. The surgeon will cut out the melanoma and some skin around it (wider or safety margin).
- In a wide local excision, small wounds are stitched up. For larger wounds, skin is pulled over the wound and stitched (skin flap), or a thin layer of skin is taken from another part of the body and placed over the wound (skin graft).
- Recovery time will vary depending on the extent of the surgery. Most people recover in one to two weeks.
- If cancer has spread to nearby lymph nodes, this is called regional melanoma.
- Lymph nodes are removed in a surgical procedure called lymph node dissection or lymphadenectomy. This procedure may cause side effects, such as shoulder, neck or hip stiffness and lymphoedema.
- Lymphoedema occurs when lymph fluid builds up and causes swelling. This can be prevented or managed.
- Treatments that are used after surgery, in case the melanoma comes back, are called adjuvant therapies.



# Treatment for advanced melanoma

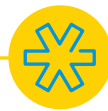
Advanced melanoma (stage 4 or metastatic melanoma) means the cancer has spread to distant skin sites, lymph nodes, internal organs or bones. Treatment may include surgery, radiotherapy, targeted therapy or immunotherapy. Palliative treatment may also be offered to help you manage your symptoms. Due to the development of more effective treatments, chemotherapy is now rarely used to treat melanoma. Your medical team will discuss the best treatment for you based on the thickness of the melanoma and how far the melanoma has spread.

## Surgery

In some cases the surgeon will be able to do a wide local excision (see page 25) to treat metastatic melanoma that involves other parts of the skin. The surgeon will also remove nearby lymph nodes if they are cancerous. This procedure is called a lymph node dissection or lymphadenectomy (see page 28).

If the melanoma has spread to internal organs, surgery may still be possible, but this will depend on a number of factors. The type of operation you have will depend on the part of your body that is affected. Talk to your medical team for more information or call Cancer Council 13 11 20.

Cancer Council produces information booklets on surgery and radiotherapy. Call **13 11 20** for free copies, or download digital versions from your local Cancer Council website.



## Radiotherapy

Radiotherapy uses x-rays to damage or kill cancer cells so they cannot multiply. Radiotherapy for melanoma might be used:

- when the cancer has spread to the lymph nodes and may not be controlled by surgery without help
- after surgery to prevent the melanoma coming back
- in combination with other treatments or, in special circumstances, on its own
- as palliative treatment when the melanoma has spread to other parts of the body, such as the bones or brain, to control cancer growth or relieve symptoms.

Before starting treatment, you will have a planning appointment where a CT (computerised tomography) scan is performed. The radiotherapy team will use the images from the scan to plan your treatment. The technician may make some small permanent tattoos or temporary marks on your skin so that the same area is targeted during each treatment session.

During treatment, you will lie on a table under a machine that aims radiation at the affected part of your body. Treatment sessions are usually given daily over one to four weeks. The number of treatment sessions will depend on the size and location of the tumour, and your general health. Each session takes about 20–30 minutes and is painless – similar to an x-ray.

### Side effects

Many people will develop temporary side effects, such as skin reactions and tiredness, during their treatment. Skin in the

treatment area may become red and sore during or immediately after treatment, and may build up over time. The side effects you experience will depend on the part of the body that receives radiotherapy and how long you receive treatment. Ask your treatment team for advice about dealing with any side effects.

External radiotherapy will not make you radioactive. It is safe for you to be with other people, including children, after your treatment.

## Targeted therapy

Targeted therapy drugs attack specific genetic changes (mutations) within cells that allow melanomas to grow and spread (see page 18), while minimising harm to healthy cells. They are generally taken as tablets (orally). Targeted therapy is most commonly used for advanced melanoma that has spread to other organs or if the melanoma has come back after treatment.

Types of targeted therapy drugs approved for use for patients with BRAF-mutated advanced melanoma include dabrafenib and trametinib. These drugs aim to block the effects of the BRAF mutation and reduce the growth of the melanoma. Other drugs may be available through clinical trials – talk to your doctor about whether you are a suitable candidate.

Some cancer treatments can affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.



Cancer cells often become resistant to targeted therapy drugs. If this happens, your doctor will change your treatment and may suggest trying another type of targeted therapy.

### Side effects

The side effects of targeted therapy will vary depending on which drug you are given. Common side effects include fever, tiredness, joint aches and pains, nausea, rash and other skin problems, diarrhoea, liver inflammation, and high blood pressure. Ask your treatment team for advice about dealing with any side effects.



It is important to discuss any side effects with your doctor immediately, including changes to your mood. If left untreated some symptoms can become life-threatening. For more information about targeted therapy and immunotherapy call Cancer Council **13 11 20**.

## Immunotherapy

Some drugs can stimulate the body's immune system to recognise and fight melanoma cancer cells. There have been a number of new developments in the use of immunotherapy to treat melanoma. Ipilimumab, nivolumab and pembrolizumab are three immunotherapy drugs that are approved for the treatment of advanced melanoma. These drugs are known as checkpoint inhibitors because they block proteins that suppress the immune response, helping the immune system to recognise and attack melanoma cancer cells. These drugs are usually administered

into a vein (intravenously). If the melanoma comes back on the skin, it may be treated using an immunotherapy cream or with an injection of an immunotherapy drug directly into the recurrence.

Around one in three people with advanced melanoma will respond to immunotherapy drugs. However, melanoma can become resistant to these drugs and tumours can start to regrow. Immunotherapy drugs are sometimes used in combination and different combinations of drugs suit different people. Treatments in this area are changing rapidly. It is important to talk to your doctor about your particular circumstances to see what therapies are appropriate for you.

## Side effects

The side effects of immunotherapy drugs will vary depending on which drugs you are given. They can include tiredness, inflammation, joint pains, diarrhoea, low hormone levels, and skin problems such as rash and itch. It's important to discuss any side effects with your medical team as soon as they appear so they can be managed appropriately. Early treatment for side effects is likely to shorten their duration. Contact your medical team if you are experiencing side effects which concern you.

Because immunotherapy drugs stimulate the immune system, they can cause major inflammatory reactions such as dermatitis, hepatitis and colitis. Consider wearing a medical alert bracelet to ensure that medical staff know you are undergoing immunotherapy treatment.





Many of the current treatments for advanced melanoma have come from testing in clinical trials (see page 24). New treatments are continually being developed and you may be asked to participate in a clinical trial to help improve therapies for melanoma.

## Palliative treatment

In some cases of advanced melanoma, the medical team may talk to you about palliative treatment. Palliative treatment aims to manage symptoms and improve people's quality of life without trying to cure the disease.

Many people think that palliative treatment is for people at the end of their life; however it may be beneficial for people at any stage of advanced melanoma. It is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve any pain and help manage other symptoms. Treatment may include radiotherapy or drug therapies.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs. The team also provides support to families and carers.

For more information or free booklets about *Palliative Care* or *Living with Advanced Cancer*, call Cancer Council 13 11 20 or download digital versions from your local Cancer Council website.





## Key points

- If melanoma has spread to other parts of your body (distant skin sites, lymph nodes or internal organs), it is called advanced or metastatic melanoma.
- Treatment options for metastatic melanoma include surgery, radiotherapy, targeted therapy or immunotherapy. You may also be able to participate in clinical trials. New developments are occurring all the time.
- The surgeon will often be able to remove the melanoma metastasis and the skin around it (wide local excision).
- Nearby lymph nodes may also be removed in a surgical procedure called lymph node dissection (lymphadenectomy).
- Radiotherapy uses x-rays to kill or damage cancer cells so they cannot multiply.
- Side effects of radiotherapy may include skin redness and soreness, and fatigue.
- Targeted therapy targets specific mutations within skin cells that signal the melanoma to grow.
- Common side effects of targeted therapy drugs include fever, tiredness, and joint aches and pains.
- Immunotherapy drugs stimulate the body's immune system to recognise and fight melanoma cancer cells.
- Common side effects of immunotherapy drugs include tiredness, inflammation of a range of organs, and joint pains.
- Palliative treatment seeks to improve quality of life without aiming to cure the cancer.



# Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.

## Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways, for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

## Sexuality, intimacy and fertility

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Call 13 11 20 for free copies of *Sexuality, Intimacy and Cancer*, *Fertility and Cancer* and *Emotions and Cancer*, or download the booklets from your local Cancer Council website.

## Changing body image

Skin cancer treatments, such as surgery and skin flaps or grafts, often leave noticeable scars. In most cases, your doctor will do everything possible to make the scars less noticeable. Scars fade with time. Various cosmetics are available to help conceal scars if you are concerned about their appearance. Your hairstyle or clothing might also cover scarring.

Give yourself time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing on the parts that have changed. Many people find it helps to talk things through with a counsellor, friend or family member.

Look Good Feel Better is a national program that helps men, women and teenagers manage the appearance-related effects of cancer treatment. For information about services in your area, visit [lgfb.org.au](http://lgfb.org.au) or call 1800 650 960.

## Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to 'normal life', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

## Follow-up appointments

After treatment, you will need regular check-ups to confirm that the cancer hasn't come back. Follow-up appointments will become less frequent if you have no further problems. Let your doctor know immediately of any health problems between appointments. Follow-up will vary depending on the type of melanoma you have. Your doctor will recommend regular skin checks, including the level of monitoring needed for your particular melanoma. Check with your doctor if you are unsure of your follow-up plan.

### Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some

people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety.

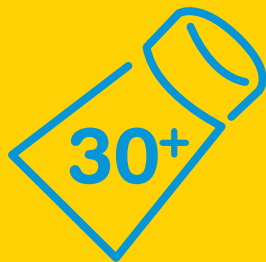
Go to [beyondblue.org.au](http://beyondblue.org.au) or call **1300 22 4636** to order a fact sheet.

## Protecting your skin from the sun

When UV levels are 3 or above, use a combination of measures to protect your skin.

### Slip on clothing

Wear clothing that covers your shoulders, neck, arms, legs and body. Choose closely woven fabric or fabric with a high ultraviolet protection factor rating.

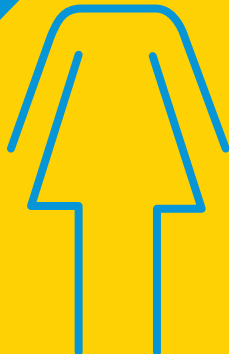


### Slop on sunscreen

Use an SPF 30+ or higher broad spectrum sunscreen. Use a water-resistant product for sports and swimming. Apply a generous amount of sunscreen 20 minutes before going out and reapply every two hours, or after swimming or any activity that causes you to sweat or rub it off.

### Slap on a hat

Wear a broad-brimmed hat that shades your face, neck and ears. Adult hats should have at least a 7.5 cm brim. Hats for children aged under 8 years should have at least a 5 cm brim, and hats for children aged 8–12 should have at least a 6 cm brim.



### Avoid sun lamps and solariums

Do not use sun lamps, solariums or tanning beds (banned for commercial use), which give off UV radiation.



### Seek shade

Use shade from trees, umbrellas, buildings or any type of canopy. UV radiation is reflective and bounces off surfaces, such as concrete, water, sand and snow. If you can see the sky, even if the direct sun is blocked, the shade will not completely protect you from UV.



### Protect children

Protect babies and children from direct exposure to sunlight. Apply SPF 30+ or higher sunscreen to the areas of a baby's or child's skin that cannot be covered with clothing.

### Slide on sunglasses

Protect your eyes with sunglasses that meet the Australian Standard AS 1067. Wrap-around styles are best. Sunglasses should be worn all year round.



### Check sun protection times every day

Use the SunSmart UV Alert to check daily sun protection times in your local area. It is available as a free SunSmart app, online ([sunsmart.com.au](http://sunsmart.com.au) or [bom.gov.au/uv](http://bom.gov.au/uv)), in the weather section of daily newspapers, or as a free website widget.



## What if the melanoma returns?

For some people melanoma does come back after treatment, which is known as a recurrence. Recurrence can be locally at the site where the melanoma was removed; in the lymph nodes; or further away in other body sites, like the lung, brain or liver. People who have had one melanoma have about five times the risk of developing a new melanoma compared with the average person of their age. It is important to be familiar with your skin, check it for changes, and visit your doctor for regular check-ups.

During follow-up appointments, your doctor will check your melanoma site and lymph nodes for any regrowth or spread. Your doctor will also check the rest of your skin for other possible melanomas.

## Sun exposure and vitamin D

Some exposure to the sun is healthy. Vitamin D, which is needed to develop and maintain healthy bones, is produced in the body when skin is exposed to UV radiation in sunlight. However, after treatment for melanoma it is important to limit your exposure to UV radiation and use a combination of sun protection measures whenever the UV index is 3 or above – see pages 44–45.

UV levels vary across Australia, according to the location, the season and the time of day. This means the amount of time you need to be in the sun to make enough vitamin D will vary. Short incidental sun exposure, such as walking from the office to get lunch, can be a good way to maintain vitamin D levels.





# Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

## Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

## Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support setting, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest because they aren't trying to protect their loved ones.

## Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as Cancer Council Online Community at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area. You can also contact Melanoma Patients Australia on 1300 88 44 50 or at [melanomapatients.org.au](http://melanomapatients.org.au) for information about melanoma support groups or support from a professional counsellor.

“ I found that my support group was a useful, safe place to express my emotions and experiences without having to censor myself to protect the feelings of other people. ” Pam



# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit [carergateway.gov.au](http://carergateway.gov.au) or call 1800 422 737.

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit [carersaustralia.com.au](http://carersaustralia.com.au) for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers' services and get a copy of the *Caring for Someone with Cancer* booklet.



# Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

## Australian

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Cancer Council Australia.....	<b>cancer.org.au</b>
Australian Melanoma Research Foundation .....	<b>melanomaresearch.com.au</b>
beyondblue.....	<b>beyondblue.org.au</b>
Cancer Australia .....	<b>canceraustralia.gov.au</b>
Carers Australia .....	<b>carersaustralia.com.au</b>
Department of Health .....	<b>health.gov.au</b>
Healthdirect Australia .....	<b>healthdirect.gov.au</b>
Australia and New Zealand Melanoma Trials Group .....	<b>anzmtg.org</b>
Melanoma Institute Australia .....	<b>melanoma.org.au</b>
Melanoma Patients Australia.....	<b>melanomapatients.org.au</b>
Melanoma WA .....	<b>melanomawa.org.au</b>
Peter MacCallum Cancer Centre.....	<b>petermac.org</b>
Skin & Cancer Foundation Inc.....	<b>skincancer.asn.au</b>
Sunsmart .....	<b>sunsmart.com.au</b>
Western Australian Melanoma Advisory Service.....	<b>wamas.org.au</b>

## International

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American Cancer Society.....	<b>cancer.org</b>
Cancer Research UK .....	<b>cancerresearchuk.org</b>
Macmillan Cancer Support (UK).....	<b>macmillan.org.uk</b>
Melanoma Research Foundation (US).....	<b>melanoma.org</b>
National Institutes of Health (US) ....	<b>medlineplus.gov/melanoma.html</b>
Skin Cancer Foundation (US).....	<b>skincancer.org</b>



## Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of melanoma do I have? How thick is it?
- Has the melanoma spread? How fast is it growing?
- Did the biopsy remove all of the melanoma?
- What treatment do you recommend and why?
- What are the risks and possible side effects of each treatment? How can these be managed?
- Will there be any scarring after the melanoma is removed?
- What are the chances I will get lymphoedema after surgery?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? If I do, what will be done about this?
- Will there be any long-term effects from treatment?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How will I know if the treatment is working?
- Is the melanoma likely to return?
- What sort of follow-up will I need?
- How often should I get my skin checked after treatment? Who should I go to for my skin checks?
- Are there any local support groups for people with melanoma?
- How can I receive the recommended levels of vitamin D to limit my sun exposure?



# Glossary

## **acral lentiginous melanoma**

A rare type of skin melanoma that occurs on the palms of the hands, soles of the feet or under the nails.

## **adjuvant treatment**

A treatment given after the primary treatment to enhance its effectiveness.

## **advanced melanoma**

Cancer that has spread deeply into the surrounding tissues or away from the original site (metastasised) and is less likely to be cured.

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a person to lose consciousness for a period of time.

## **basal cell**

A type of cell that makes up the lower layer of the epidermis.

## **basal cell carcinoma (BCC)**

A type of skin cancer that develops in the basal cells of the epidermis.

## **benign**

Not cancerous or malignant. Benign tumours are not able to spread to other parts of the body.

## **biopsy**

The removal of a small sample of tissue from the body for examination under a microscope to help diagnose a disease.

## **BRAF gene mutation**

A non-inherited gene change which can signal cancer cells to multiply. It increases the risk of developing a melanoma.

## **Breslow thickness**

A description of a melanoma's thickness in millimetres from the top layer of the skin to its deepest point in the skin.

## **cells**

The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions.

## **chemotherapy**

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

## **Clark level**

A number (1–5) that describes how far a melanoma has penetrated into the skin.

## **CT scan**

Computerised tomography scan. This scan uses x-rays to create a detailed, cross-sectional picture of the body.

## **cutaneous melanoma**

Melanoma that starts in the skin.

## **dermis**

The lower layer of the two main layers that make up the skin.

## **desmoplastic melanoma**

An uncommon type of skin melanoma.

## **epidermis**

The top, outer layer of the two main layers that make up the skin.

## **excision biopsy**

A type of biopsy where a lesion is surgically removed (excised) so it can be looked at under a microscope to help diagnose a disease.

## **genes**

The microscopic units that determine how the body's cells grow and behave. Genes are found in every cell of the body and are inherited from both parents.

## **immunotherapy**

The prevention or treatment of disease using substances that alter the immune system's response. May also be called biological therapy.

## **lentigo maligna melanoma**

A type of skin melanoma that develops in a large freckle (lentigo maligna). Also called melanoma in situ.

## **lesion**

An area of abnormal tissue.

## **localised melanoma**

A melanoma that has not spread from its starting point to lymph nodes or other organs.

## **lymph nodes**

Small, bean-shaped glands that form part of the lymphatic system. They collect and help to destroy bacteria and viruses. Also called lymph glands.

## **lymph vessels**

Thin tubes that carry the body's tissue fluid (lymph) all over the body.

## **lymphadenectomy**

Removal of the lymph nodes from a part of the body. Also called a lymph node dissection.

## **lymphatic system**

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues,

absorbs fatty acids and transports fat, and produces immune cells. Includes the thymus, bone marrow, spleen and lymph nodes.

## **lymphoedema**

Swelling caused by a build-up of lymph fluid. This happens when lymph vessels or nodes don't drain properly.

## **malignant**

Cancer. Malignant cells can spread (metastasise) and eventually cause death if they cannot be treated.

## **margin**

When a melanoma is surgically removed, some surrounding tissue will be removed with it. If this surrounding tissue does not contain any cancer cells, it is said to be a clear, negative or clean margin. If it does contain cancer cells, it is called a positive or close margin.

## **melanin**

Dark pigment produced in melanocytes that gives skin its colour.

## **melanocyte**

One of the three types of cells that make up the skin's epidermis. Melanocytes produce melanin.

## **melanoma**

Cancer of the melanocytes. The cancer usually appears on the skin but may affect the nervous system, eye or mucous membranes (e.g. the lining of the mouth and nasal passages).

## **melanoma in situ**

An early melanoma that is confined to the upper layer of the skin (epidermis) and has not penetrated into the deeper tissue (dermis).

**metastasis (plural: metastases)**

A cancer that has spread from a primary cancer in another part of the body. Also known as secondary cancer.

**mole**

See naevus.

**mucosa**

Moist tissue that lines organs of the body, such as the digestive tract, lungs and nose.

**naevus (plural: naevi)**

A small dark spot on the skin that arises from skin cells called melanocytes. Also called a mole.

**nodular melanoma**

A type of skin melanoma. Makes up about 10–15% of melanomas, and is often aggressive.

**non-melanoma skin cancer**

Skin cancer that doesn't develop from the melanocytic cells, e.g. basal cell and squamous cell cancer.

**NRAS gene mutation**

A non-inherited gene change which can cause cells to grow and divide uncontrollably. It increases the risk of developing a melanoma.

**PET scan**

Positron emission tomography scan. A person is injected with a small amount of radioactive glucose solution to show cancerous areas in the scan.

**primary cancer**

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

**primary site**

The part of the body where the cancer first developed.

**prognosis**

The predicted outcome of a person's disease.

**radiotherapy**

The use of radiation, such as x-rays, gamma rays, electron beams or protons, to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

**risk factor**

A substance or condition that increases an individual's chance of developing a particular type of cancer.

**sentinel lymph node biopsy**

A surgical procedure used to determine whether a melanoma has spread from the primary site to the lymphatic system.

**sentinel node**

The first lymph node to receive lymph fluid directly from a tumour.

**seroma**

A collection of fluid under a wound after an operation.

**skin flap**

Nearby skin or fatty tissue that is pulled over the wound left by the removal of a melanoma and stitched.

**skin graft**

A layer of skin from another part of the body that is stitched over the wound left by the removal of a melanoma.

**squamous cell**

A type of cell that makes up the top layer of the epidermis.



### squamous cell carcinoma (SCC)

A type of skin cancer that begins in the squamous cells of the epidermis.

### stage

The extent of a cancer and whether the disease has spread from the original site to other parts of the body.

### superficial spreading melanoma

The most common skin melanoma type, making up 55–60% of all cases.

### targeted therapy

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread.

### tissue

A collection of cells that make up a part of the body.

### tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

### ultraviolet (UV) radiation

The part of sunlight that causes tanning, sunburn and skin damage. It is also produced by solariums, sun lamps and tanning beds. UV radiation cannot be seen or felt.

### UV Index

An internationally standard measure of the intensity of the sun's ultraviolet radiation.

### wide local excision

A surgical procedure to remove a melanoma with some of the healthy tissue around it.

### Can't find a word here?

For more cancer-related words, visit:

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

## References

1. R Dummer et al. on behalf of the ESMO Guidelines Committee, 'Cutaneous melanoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up', *Annals of Oncology*, vol. 26, suppl. 5, 2015, pp. v126–v132. doi:10.1093/annonc/mdv297.
2. Cancer Council Australia Melanoma Guidelines Working Party, *Clinical practice guidelines for the diagnosis and management of melanoma (features of melanoma, biopsy, sentinel node biopsy, excision margins)*, Cancer Council Australia, Sydney, 2016. Available from: <http://wiki.cancer.org.au/australia/Guidelines:Melanoma> (accessed 2 November 2016).
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4. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia: an overview 2014*, AIHW, Canberra, 2016.
5. M Boniol et al., 'Cutaneous melanoma attributable to sunbed use: systematic review and meta-analysis', *BMJ*, vol. 345:e4757, 2012.



# How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



# Cancer Council 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

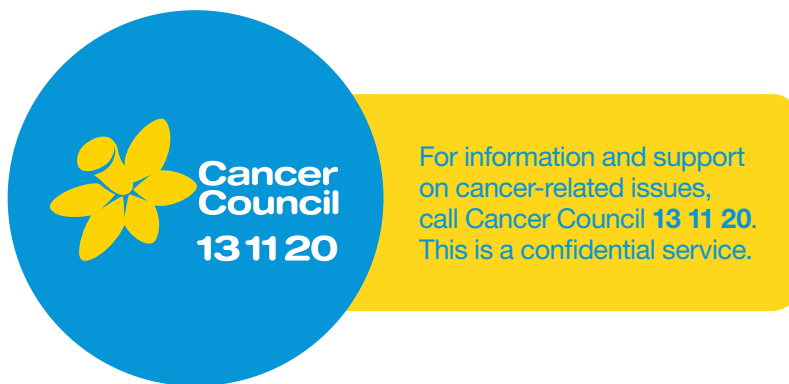
Cancer Council services and programs vary in each area.  
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**



**If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.**  
[www.relayservice.gov.au](http://www.relayservice.gov.au)



## Visit your local Cancer Council website

**Cancer Council ACT**  
actcancer.org

**Cancer Council NSW**  
cancercouncil.com.au

**Cancer Council NT**  
nt.cancer.org.au

**Cancer Council Queensland**  
cancerqld.org.au

**Cancer Council SA**  
cancersa.org.au

**Cancer Council Tasmania**  
cancertas.org.au

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cancervic.org.au

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cancerwa.asn.au

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cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*