



# 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

A guide for people with cancer, their families and friends

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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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### 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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# About this booklet

This booklet has been prepared to help you understand more about melanoma, a type of skin cancer. Other types of skin cancer include basal cell carcinoma (BCC) and squamous cell carcinoma (SCC), which are often called non-melanoma skin cancers.

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. It also includes information about support services. We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 51).

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 (see page 52). You may also like to pass this booklet to 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</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. You can also visit your local Cancer Council website (see back cover).



**Cancer  
Council  
13 11 20**

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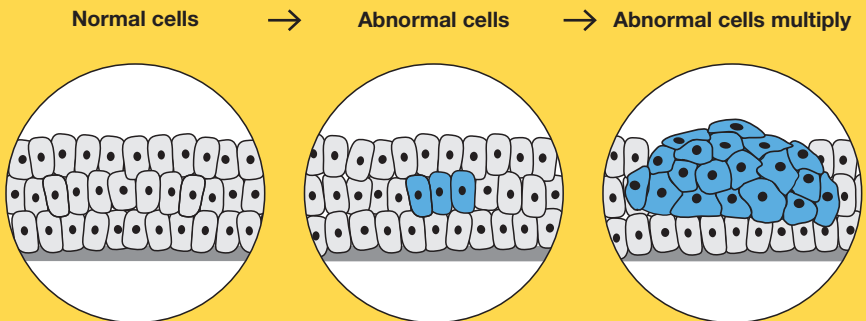
# What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. 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, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as melanoma, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancers. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

## How cancer starts

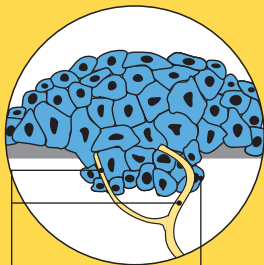


cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops in a tissue or organ is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer 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 liver is called metastatic melanoma, even though the main symptoms may be coming from the liver.

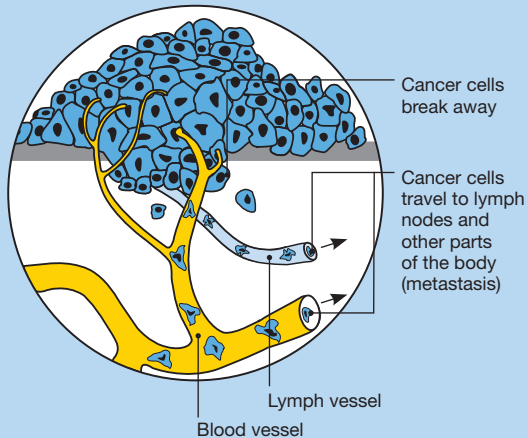
## How cancer spreads

### → Malignant cancer



Grows own  
blood vessels  
(angiogenesis)

Invades  
surrounding  
tissue



Cancer cells  
break away

Cancer cells  
travel to lymph  
nodes and  
other parts of  
the body  
(metastasis)

Lymph vessel

Blood vessel



# The skin

The skin is the largest organ of 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.

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 the skin. Over time the body sheds these dead skin cells.

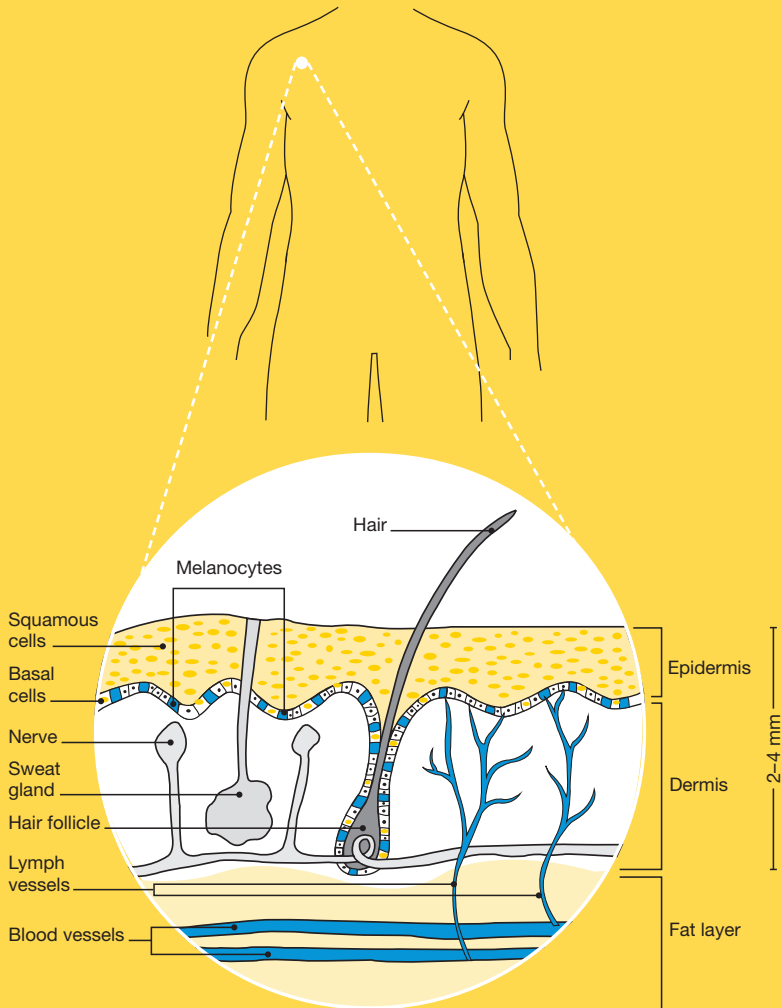
**Basal cells** – These block-like cells make up the lower layer of the epidermis and multiply constantly. As they age, they move up within the epidermis and flatten out to form squamous cells.

**Melanocytes** – These cells sit between the basal cells 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 that sits below the epidermis. It is made up of fibrous tissue and contains the roots of hair (follicles), sweat glands, blood vessels, lymph vessels, and nerves.



## The layers of the skin





## Key questions

### Q: What is melanoma?

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

Although it is one of the less common types of skin cancer, melanoma is considered the most serious 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: How common is melanoma?

**A:** Australia and New Zealand have the highest rates of melanoma in the world. More than 13,000 people are diagnosed with melanoma in Australia every year. Melanoma is the third most common cancer in both men and women (excluding non-melanoma skin cancers). One in 13 men and 1 in 22 women will be diagnosed with melanoma before age 85.<sup>2</sup>



This booklet is about melanoma. If you are looking for information about non-melanoma skin cancers (basal cell or squamous cell carcinomas), see our *Understanding Skin Cancer* booklet.

## Q: What are the different types?

**A:** Melanoma of the skin is known as cutaneous melanoma. The major subtypes are:

**Superficial spreading melanoma** – This makes up 55–60% of all melanomas. 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 grows on the surface of the skin, or an existing spot, freckle or mole that changes size, colour or shape. It can develop on any part of the body but especially the trunk. 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 (nodule) on the surface of the skin that is pink, red, brown or black and feels firm to touch. It may develop a crusty surface that bleeds easily. Nodular melanoma is most commonly found in older people on 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 a rare type of melanoma (about 1–2% of all cases). It is most commonly found on the 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 most often presents as a long streak of pigment in the nail. It tends to grow slowly before becoming invasive.

**Desmoplastic melanoma** – This is another rare type of melanoma (about 1% of cases). It often appears on the head or neck of sun-damaged skin. Desmoplastic melanoma presents as a firm, growing frequently skin-coloured lump, sometimes described as scar-like. Some have a patch of overlying pigmentation, and can be difficult to diagnose.

Some rarer types of melanoma start in parts of the body other than the skin. Mucosal melanoma can start in the tissues in the mouth, anus, urethra, vagina or nasal passages. Ocular melanoma can start inside the eye. Melanoma can also start in the central nervous system. To find out more, call Cancer Council 13 11 20.



For an overview of what to expect during all stages of your cancer care, visit [cancerpathways.org.au/optimal-care-pathways/melanoma](https://cancerpathways.org.au/optimal-care-pathways/melanoma). This is a short guide to what is recommended, from diagnosis to treatment and beyond.



Examining your skin regularly, or as recommended by your general practitioner (GP), will help you notice any new or changing spots.

## Q: What are the signs?

**A:** Melanoma can vary greatly in the way it looks. In people who have lots of moles, melanoma usually stands out and looks different from the other moles. The first sign is often a new spot or occasionally 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 depths 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 shape (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.

New moles can appear during childhood and through to the 30s and 40s, as well as during pregnancy. However, adults should see their doctor to get a new mole examined, particularly if it is noticeably different from other moles or is raised, firm and growing. Even if you have had a mole checked before and it was considered benign, it is important to regularly check your skin for any change in shape, size or colour in the future. Talk to your doctor immediately about any changes.

## Q: What causes melanoma?

**A:** The main cause of all types of skin cancer 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 solariums have a significantly greater risk of developing melanoma.

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 above the elbow on the arms and more than 100 on the body
- pale, fair or freckled skin, especially if it burns easily and doesn't tan
- lots of 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
- a pattern of 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 from using immune suppression medicines for a long time.

Overexposure to UV radiation can permanently damage the skin. This damage adds up over time. Childhood exposure to UV radiation increases the risk of skin cancer later in life, although sun protection 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. Often, this is because family members have 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.

When two or more close relatives (parent, sibling or child) have been diagnosed with melanoma, especially if the person has been diagnosed with more than one melanoma on different areas of the skin and/or diagnosed with melanoma before the age of 40, then they may have an inherited faulty gene.

People with a strong family history of melanoma should protect and monitor their skin themselves, and have a professional skin check by a doctor every year from their early 20s. 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. Visit [genetics.edu.au](http://genetics.edu.au) to find a family cancer clinic near you.

To find out more, call Cancer Council **13 11 20**.

## Q: Which health professionals will I see?

**A:** Your GP will probably arrange the first tests to assess your symptoms. If these tests confirm melanoma, you will usually be referred to a specialist, such as a dermatologist or surgeon. The specialist will arrange further tests. If melanoma is diagnosed, the specialist will consider treatment options. These options may be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting.

During and after treatment, you may also see a range of health professionals who specialise in different aspects of your care, especially if you have a melanoma with a Breslow thickness greater than 1 mm (see page 19), or if the melanoma has spread.

### 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.

If you are referred to a multidisciplinary melanoma unit by your GP, you will be able to talk to one or more medical specialists who will answer your questions, and recommend the most suitable treatment. The best treatment pathway will depend on the test results.

To find a specialist melanoma unit near you, ask your doctor, call Cancer Council 13 11 20 or visit Melanoma Patients Australia at [melanomapatients.org.au/about-melanoma/treatment-centres](http://melanomapatients.org.au/about-melanoma/treatment-centres).



## Health professionals you may see

<b>dermatologist*</b>	diagnoses, treats and manages skin conditions, including skin cancer
<b>general surgeon*</b>	performs surgery to remove early melanoma; skin reconstruction; and surgery on the lymph nodes
<b>reconstructive (plastic) surgeon*</b>	performs surgery that restores, repairs or reconstructs the body's appearance and function
<b>surgical oncologist*</b>	performs surgery to remove melanoma and conducts more complex surgery on the lymph nodes and other organs
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
<b>radiation oncologist*</b>	plans and delivers radiation therapy
<b>cancer care coordinator</b>	coordinates care, liaises with MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
<b>counsellor, social worker, psychologist</b>	help you manage your emotional response to diagnosis and treatment
<b>physiotherapist, occupational therapist</b>	assist with physical and practical issues, including restoring movement and mobility after treatment
<b>palliative care specialist* and nurses</b>	work closely with the GP and cancer specialists to help control symptoms and maintain quality of life

\* Specialist doctor








# Diagnosis

## Physical examination

If you notice any changes to your skin, your doctor will examine you, looking carefully at any spots you have identified as changed or suspicious. The doctor will ask if you or your family have a history of melanoma. Using a handheld magnifying instrument called a dermoscope, the doctor will examine the spot more closely and consider the criteria known as “ABCDE”.

### ABCDE signs of melanoma

<b>Asymmetry</b>	Are the halves of each mole different?	
<b>Border</b>	Are the edges uneven, scalloped or notched?	
<b>Colour</b>	Are there differing shades and colour patches?	
<b>Diameter</b>	Is the spot greater than 6 mm across?	
<b>Evolving</b>	Has the spot changed over time (size, shape, surface, colour, bleeding, itching)?	

Some types of melanoma, such as nodular and desmoplastic melanomas, don't fit the “ABCDE” criteria, so your doctor may also assess whether the spot is elevated, firm or growing.

## Removing the mole (excision biopsy)

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

For this procedure, you will have an injection of local anaesthetic to numb the area. The doctor will use a scalpel to remove the spot and a small amount (2 mm margin) 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 work out if it contains melanoma cells. Results are usually ready within a week. For information about what the pathology results mean, see page 19.

You'll have a follow-up appointment to check the wound and remove the stitches. If a diagnosis of melanoma is confirmed, you will probably need further surgery, such as a wide local excision (see pages 25–26).

## Checking 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. To test whether the melanoma has spread, your doctor may recommend that you have a fine needle biopsy or a sentinel lymph node biopsy.

**Fine needle biopsy** – A thin needle is used to take a sample of cells from an enlarged lymph node. Sometimes an ultrasound helps guide the needle into place. The sample is then examined under a microscope to see if it contains cancer cells.

**Sentinel lymph node biopsy** – If the Breslow thickness (see box opposite) of the melanoma is over 1 mm or sometimes for people with melanoma between 0.8 mm to 1 mm, you may be offered a sentinel lymph node biopsy. This biopsy finds and removes the first lymph node/s that the melanoma would be likely to spread to (the sentinel node/s). It is usually done at the same time as the wide local excision (see pages 25–26).

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

To find the sentinel node/s, a small amount of radioactive dye is injected into the area where the melanoma was found. The surgeon removes the node that absorbs the injected fluid to check for cancer cells. If they are found in the sentinel lymph node, further tests such as ultrasound, CT or PET scans may be done during follow-up and systemic treatment may be offered (see page 31).

## Pathology report

If you have melanoma, the report from the pathologist will provide your treatment team with information to help determine the stage, plan treatment, and work out your prognosis. You can ask your doctor for a copy of the results, and discuss the results with them. The following factors may be included:

**Breslow thickness** – This is a measure of the thickness of the tumour in millimetres to its deepest point in the skin. The thicker a melanoma, the more likely it could return (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.

**Ulceration** – The breakdown or loss of the outer layer of skin over the tumour is a sign of rapid tumour growth.

**Mitotic rate** – Mitosis is the process by which one cell divides into two. The pathologist counts the number of actively dividing cells to calculate how quickly the melanoma cells are dividing.

**Clark level** – This describes how many layers of skin the tumour has gone through. It is rated I–V, with I the shallowest and V the deepest. Breslow thickness is much 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 abnormal tissue (lesion) was from the edge.

**Regression** – The report will note any lymphocytes (immune cells) within the melanoma and any evidence of whether some melanoma cells have been destroyed by the immune system and replaced with scar tissue.

## Staging melanoma

The test results will help your doctors assign a stage to describe the melanoma. You may also have some other diagnostic tests, including blood tests and imaging tests (ultrasound, CT scan or PET scan), to work out whether the melanoma has spread from the primary site to other parts of the body. Staging the melanoma helps your health care team recommend the most appropriate treatment for you.

### Stages of melanoma

<b>stage 0 (in situ)</b>	The melanoma is confined to the top, outer layer of the skin.
<b>stage I</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 II</b>	The melanoma has not moved beyond the primary site and is greater than 1 mm and ulcerated or greater than 2 mm in thickness (may or may not have ulceration).
<b>stage III</b>	The melanoma has spread to lymph nodes near the primary site, to nearby skin or to tissues under the skin (subcutaneous).
<b>stage IV</b>	The melanoma has spread to distant skin and/or other parts of the body such as the lungs, liver, brain, bone or distant lymph nodes.

Stages 0, I and II are called early melanoma, while stage III is referred to as regional melanoma. Stage IV melanoma has spread to other parts of the body and is called advanced or metastatic.

## Gene mutation testing

If the melanoma has spread (stage III or IV), further tests can help work out whether you have a particular gene change (mutation) that may be causing the cancer cells to multiply and grow. These genetic mutations are due to changes in cancer cells – they are not the same thing as genes passed through families.

Approximately 40% of people with melanoma have a mutation in the BRAF gene and approximately 15% have a mutation in the NRAS gene. C-KIT is a rare mutation affecting less than 4% of people.

Genetic tests can be done on the sample removed during surgery. The test results will help doctors decide whether you are offered immunotherapy or targeted therapy (see pages 34–35).

## 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 discuss any concerns you have.

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 layer of the skin (dermis), the greater the risk that it could spread to nearby lymph nodes or other organs. In recent years, clinical trials have led to new treatments that continue to improve the prognosis for people with melanoma that has spread from the primary site (advanced melanoma).



## Key points about diagnosing melanoma

### Main tests

Tests to diagnose melanoma include:

- examination of the suspicious spot or mole, and any other moles on your body
- removing 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.

### Other tests

Your doctor will feel the nearby lymph nodes to work out if the melanoma has spread to other parts of the body. To check the lymph nodes for cancer cells, you may have a:

- fine needle biopsy
- sentinel lymph node biopsy.

### Staging and prognosis

The stage shows how far the melanoma has spread. Early melanoma is stages 0–II.

Regional melanoma is stage III. If the melanoma has spread, it is considered stage IV. In these cases, gene mutation testing of tissue samples is recommended.

Your doctor may talk to you about the prognosis, which is the expected outcome for your type and stage of cancer.





# 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, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 14) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

**Record the details** – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes or recording the discussion can help. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 51 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

**Consider a second opinion** – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist 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 second specialist.

**It's your decision** – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

➤ See our *Cancer Care and Your Rights* booklet.

### Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time.

For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

➤ See our *Understanding Clinical Trials and Research* booklet.



# Treatment for early melanoma

Melanoma that is found early (stages 0–II or localised melanoma) can generally be treated successfully with surgery. If the melanoma has spread to nearby lymph nodes or tissues (stage III or regional melanoma), treatment may also include removing lymph nodes and additional (adjuvant) treatments.

## Surgery

Surgery to remove the mole is the main treatment for early melanoma, and it can also be the only treatment you need.

### Wide local excision

Even though the excision biopsy to diagnose melanoma (see page 17) often removes the melanoma, a doctor or surgeon may also do a procedure called wide local excision. This means removing more normal-looking skin from around the melanoma (wider margin).

Removing more tissue around the melanoma reduces the risk of it coming back (recurring) at that site. In the latest melanoma guidelines, it is recommended that the 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.<sup>1</sup>



A pathologist will check the tissue around the melanoma for cancer cells. If the sample doesn't contain any cancer cells, it is called a clear margin. If the margins aren't clear, you may need further surgery.

A wide local excision is often performed as a day procedure using a 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 usually be offered a sentinel lymph node biopsy (see page 18) at the same time.

➤ See our *Understanding Surgery* booklet.

## Repairing the wound

Most people will be able to have the wound closed with stitches. You will have a scar but this will become less noticeable with time.

If a large area of skin is removed, the wound may be too big to close with stitches. In this case, the surgeon may repair it using skin from another part of your body. This can be done in two ways:

**Skin flap** – nearby skin and fatty tissue are lifted and moved over the wound from the edges and stitched.

**Skin graft** – a layer of skin is taken from another part of your body (usually the thigh or neck) and placed over the area where the melanoma was removed. The skin grows back quickly over a few weeks.

The decision about whether to do a skin flap or graft 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. After several days, it will be checked to see if the wound is healing properly. If you had a skin graft, you will also have dressings on any area that had skin removed for the graft.

## What to expect after surgery

### Pain relief

The area around the wide local excision may feel tight and tender for a few days. Your doctor will prescribe painkillers if necessary. If you have a skin graft, the area that had skin removed may look red and raw immediately after the operation. Over a few weeks, this area will heal and the redness will fade.



### Recovery time

The time it takes to recover will vary depending on the thickness of the melanoma and the extent of the surgery required. Most people recover in a week or two. Ask your doctor how long you should wait before returning to your usual exercise activities.

### Wound care

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 heal and a new one is required.



### When to seek advice

Talk to your doctor about any side effects such as bleeding, bruising, infection, scarring or numbness you may have after surgery.

## Removing lymph nodes

If your doctor's examination, ultrasound or lymph node biopsy shows that the melanoma has spread to your lymph nodes (regional melanoma or stage III), you will have scans regularly and, in some cases, may be offered immunotherapy or targeted therapy (systemic treatment). If melanoma has spread to lymph nodes and caused a lump, the lymph nodes will be removed in an operation called a lymph node dissection or lymphadenectomy. This is performed under a general anaesthetic and requires a longer stay in hospital. Usually only the lymph nodes near the melanoma are removed.

## Side effects of lymph node dissection

Having your lymph nodes removed can cause side effects, such as:

**Wound pain** – Most people will have some pain after the operation, which usually improves as the wound heals. For some people, the pain may be ongoing, 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 do gentle exercises or 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 is drained by having a needle inserted into the fluid-filled cavity after surgery.

## Lymphoedema

If lymph nodes have been surgically removed, your neck, arm or leg may swell. This is called lymphoedema. It happens when lymph fluid builds up in the affected part of the body because the lymphatic system is not working as it should.

The chance of developing lymphoedema following melanoma treatment depends on the extent of the surgery and whether you've had radiation therapy (see page 36) that has damaged the lymph nodes. It can develop a few weeks, or even several years, after treatment. Although lymphoedema may be permanent, it can usually be managed, especially if treated at the earliest sign of swelling or heaviness.

### How to prevent and/or manage lymphoedema

- Keep the skin healthy and unbroken to reduce the risk of infection.
- Wear a professionally fitted compression garment if recommended by your doctor or lymphoedema practitioner.
- Always wear gloves for gardening, outdoor work and housework.
- Moisturise your skin daily to prevent dry, irritated skin.
- Protect your skin from the sun (see pages 44–45).
- Don't pick or bite your nails, or cut your cuticles.
- Try to avoid scratches from pets, insect bites, thorns, or pricking your fingers.
- Do regular exercise to help the lymph fluid flow, such as swimming, bike riding or yoga.
- Massage the affected area to help move lymph fluid.
- Avoid having blood taken or blood pressure done on the arm on the affected side.
- Visit [lymphoedema.org.au](http://lymphoedema.org.au) to find a lymphoedema practitioner or ask your doctor for a referral.
- If your skin feels swollen or hot, see your doctor as soon as possible as these may be signs of infection.
- See our *Understanding Lymphoedema* fact sheet.



## Pete's story

I spent my childhood in the sun. Growing up I was always outside kicking the footy or hanging out at the beach. In the 60s and 70s, using sunscreen was considered optional, and having a sunburnt nose and shoulders was mandatory.

This all changed in my early 20s. I realised through skin cancer ads that my fair skin and blue eyes meant I was more at risk. I also have lots of moles, mostly on my arms and body. So I started covering up, using sunscreen and wearing a hat. And I now see my doctor for regular skin checks.

At one of these appointments, the doctor thought a spot on my arm looked suspicious and removed it. The biopsy was pretty simple and didn't hurt. I had it done in his office during my lunchbreak.

The mole was sent to the pathologist for testing and within a few days the doctor called

to ask me to come back in for further surgery. I did suspect that it might be a melanoma but I was still shocked when this was confirmed.

The doctor said that we'd spotted the melanoma early and that it was likely the biopsy had removed it all, but that it would be good to take a 5 mm margin to be sure. I had some local anaesthetic, he cut it out and then it was closed up with stitches. The tissue was sent to pathology, and I was relieved when the doctor called to say it was fine and no further treatment was needed.

After the wide local excision, the wound looked red and was sore, but this improved within four weeks. I was given a cream to apply to my arm to help the scar heal.

I found the whole experience rattled me a bit. I'm thankful it was found early and the treatment was straightforward.



## Adjuvant treatment

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

Some treatments enter the bloodstream and travel throughout the body. This is known as systemic treatment, and includes:

- **immunotherapy** – drugs that help the body's immune system to recognise and fight some types of cancer cells
- **targeted therapy** – drugs that attack specific features within cancer cells known as molecular targets to stop the cancer growing and spreading.

In some cases, people may be offered radiation therapy (also known as radiotherapy). This is the use of targeted radiation to damage or kill cancer cells.

For further information about targeted therapy, immunotherapy and radiation therapy, see the *Treatment for advanced melanoma* chapter on pages 34–37. You may also be offered an opportunity to participate in a clinical trial (see page 24).



## Key points about treating early or localised melanoma

### What it is

Melanoma is a type of skin cancer. Early or localised melanoma has not spread outside the primary site.

### The main treatment

The main treatment is surgery to remove the suspicious area.

### How surgery is done

Surgery for melanoma may include:

- wide local excision – cuts out the melanoma and some skin around it (wider margin)
- lymph node dissection or lymphadenectomy – removes lymph nodes if cancer has spread to nearby lymph nodes (regional melanoma or stage III).

### Other treatment options

You may also have other types of treatment after surgery to reduce the risk of the melanoma coming back. This is called adjuvant treatment, and may include:

- immunotherapy – drugs to help stimulate the body's immune system to recognise and fight melanoma
- targeted therapy – drugs to attack specific features of cancer cells that allow cancer to grow and spread
- radiation therapy – use of targeted radiation to damage cancer cells.



# Treatment for advanced melanoma

When melanoma has spread to distant lymph nodes or other internal organs or bones (stage IV), it is known as advanced melanoma or metastatic melanoma. Treatment may include surgery, systemic treatment with immunotherapy or targeted therapy, and radiation therapy. Palliative treatment may also be offered to help manage your symptoms and improve quality of life.

Since the development of more effective treatments, chemotherapy is rarely used to treat melanoma.

Treatment for advanced melanoma is complex and it is best that you are treated by a specialist melanoma unit (see page 14). The team will discuss the best treatment for you based on the thickness of the melanoma and how far the melanoma has spread.

- ▶ See our booklets and fact sheets on surgery, targeted therapy, immunotherapy and radiation therapy.

## Surgery

In some cases, surgery may be recommended for people with advanced melanoma. Surgery is used to remove melanoma from areas on the skin, lymph nodes (see page 28), or other organs such as the lung, brain or bowel.

Talk to your treatment team about what is involved and what recovery will be like. Your suitability for surgery will be discussed with a multidisciplinary team (see page 14). They will also consider other options including systemic treatment, radiation therapy and other local therapies.

## Immunotherapy

There have been several advances in using immunotherapy drugs known as checkpoint inhibitors to treat melanoma. On the surface of the body's immune cells are proteins called "checkpoints" that stop the immune system from attacking cancer cells. Checkpoint inhibitors block these proteins so the immune cells can recognise and attack the melanoma. Checkpoint inhibitors approved for advanced melanoma include ipilimumab, nivolumab and pembrolizumab. These drugs are usually given into a vein (intravenously).

Checkpoint inhibitors do not work for all advanced melanoma, but some people have had very encouraging results. Immunotherapy drugs are sometimes used in combination, and different combinations of drugs work for different people. Treatments in this area are changing rapidly. Talk to your doctor about whether immunotherapy is appropriate for you.

### Side effects of immunotherapy

The side effects of immunotherapy drugs will vary depending on which drugs you are given. Immunotherapy can cause inflammation in any of the organs in the body, which can lead to side effects such as joint pain, diarrhoea or skin problems such as an itchy rash.

Autoimmune disease may develop and this is generally monitored closely. 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 how long they last. Let your medical team know if you are experiencing side effects that concern you.

## Targeted therapy

New types of drugs known as targeted therapy attack specific genetic mutations within cancer cells (see page 21), 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 surgery.

Several different targeted therapy drugs have been approved for people who have the BRAF mutation. Drugs are often used together to help block the effects of the BRAF mutation and reduce the growth of the melanoma. Drugs for NRAS and C-KIT mutations may be available through clinical trials – talk to your doctor about whether you are a suitable candidate.

Cancer cells may become resistant to targeted therapy drugs over time. If this happens, your doctor will suggest trying another type of systemic therapy.

## Side effects of targeted therapy

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



It is important to let your doctor know immediately of any side effects. If left untreated, some side effects can become serious.

## Radiation therapy

Also known as radiotherapy, radiation therapy is the use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply and spread. Radiation therapy may be offered on its own or in combination with other treatments, and may be recommended:

- when the cancer has spread to the lymph nodes
- after surgery to prevent the melanoma coming back
- as palliative treatment to improve quality of life by relieving pain and other symptoms (see opposite).

Before starting treatment, you will have a planning appointment where a CT scan is performed. The radiation therapy 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 having an x-ray.

### **Stereotactic body radiation therapy (SBRT)**

This is a way of delivering highly focused radiation therapy to the tumour, while the surrounding tissue receives a low dose. It is delivered from multiple beams that meet at the tumour. SBRT often involves four treatment sessions over a couple of weeks.

## Side effects of radiation therapy

The side effects you experience will depend on the part of the body that receives radiation therapy and how long you receive treatment. Many people will develop temporary side effects, such as skin reactions and tiredness, during treatment. Skin in the treatment area may become red and sore during or immediately after radiation therapy, and these side effects may build up over time. Ask your treatment team for advice about dealing with any side effects.

## Palliative treatment

In some cases of advanced melanoma, the medical team may talk to you about palliative treatment. Palliative treatment aims to manage symptoms without trying to cure the disease. It can be used at any stage of advanced cancer to improve quality of life and does not mean giving up hope. Rather, 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 radiation therapy or drug therapies.

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

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.



## Key points about treating advanced melanoma

### What it is

If melanoma has spread to other parts of your body (distant skin sites, distant lymph nodes or internal organs or bones), it is called advanced or metastatic melanoma.

### Choice of treatment

Treatment will depend on test results and whether the cancer has a gene mutation. You may also be able to participate in clinical trials. New developments are occurring all the time.

### Treatment options

Treatment for advanced melanoma may include:

- surgery – removes the melanoma metastasis
- lymph node dissection (lymphadenectomy) – surgically removes nearby lymph nodes
- immunotherapy – uses drugs to help stimulate the body's immune system recognise and fight melanoma
- targeted therapy – uses drugs that attack specific features of cancer cells
- radiation therapy – uses targeted radiation to damage cancer cells
- palliative treatment – seeks to improve quality of life without aiming to cure the cancer.

### Side effects

- Immunotherapy drugs can cause inflammation of any organs in the body, and joint pain.
- Targeted therapy can cause fever, tiredness, and joint aches and pains.
- Radiation therapy may cause skin redness and fatigue.





# Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

**Eating well** – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

➤ See our *Nutrition and Cancer* booklet.

**Staying active** – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

**Complementary therapies** – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

**Work and money** – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

› See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

**Relationships** – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

› See our *Emotions and Cancer* booklet.

**Sexuality** – 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.

› See our *Sexuality, Intimacy and Cancer* booklet.

**Contraception and fertility** – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

› See our *Fertility and Cancer* booklet.



# Life after melanoma

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 that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”. It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

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.

► See our *Living Well After Cancer* booklet.

## 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

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call **beyondblue** on **1300 22 4636** or visit **[beyondblue.org.au](http://beyondblue.org.au)**. For 24-hour crisis support, call Lifeline **13 11 14** or visit **[lifeline.org.au](http://lifeline.org.au)**.

## Follow-up appointments

After treatment ends, you will need regular skin checks to confirm that the melanoma hasn't come back or spread.

The follow-up plan will vary depending on the stage, and more frequent visits are recommended for people with advanced melanoma. People who had a stage I melanoma need to see their doctor for yearly skin checks, while people with stage II melanoma will need follow-up every 6 months for several years. People with stage III melanoma will be monitored every 3 months for two years. Your doctor can give you more details of your follow-up plan.

When a follow-up appointment or test is approaching, many people may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

## UV Index and sun protection times

The UV Index shows the intensity of the sun's UV radiation using a scale that begins at 0 and has no upper limit. An index of 3 or above indicates that UV levels are high enough to damage skin, so sun protection is recommended (see pages 44–45).

The daily sun protection times tell you the times of the day the UV Index levels are forecast to be 3 or higher. The sun protection times vary according to your location and will change throughout the year.

In general, during summer in Australia, all states experience long periods during the day when the UV Index is 3 or above. In late autumn and winter in southern Australia, the UV Index may fall below 3 and sun protection is not necessary.

## Sun exposure and vitamin D

UV radiation from the sun causes skin cancer, but it is also the best source of vitamin D, which is needed to develop and maintain healthy bones. The amount of sunlight you need for vitamin D depends on several factors, including the UV level, your skin type and your lifestyle.

UV levels vary across Australia, so the time you need to spend in the sun will be determined by your location, the season and the time of day, cloud coverage and the environment. (For more information on the UV Index, see opposite.)

The body can only absorb a limited amount of vitamin D at a time. Getting more sun than recommended does not increase your vitamin D levels, but it does increase your skin cancer risk. For most people, just 15–20 minutes of incidental sun exposure, such as walking from the office to get lunch or hanging out the washing, is enough to produce the required vitamin D level.

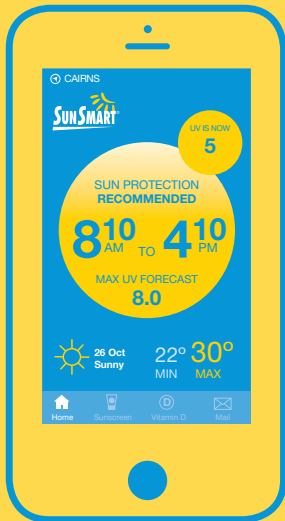
Getting too much UV is not recommended, even for people with a vitamin D deficiency. After a melanoma diagnosis, if you are concerned about vitamin D deficiency talk to your doctor about the best ways to maintain vitamin D while reducing your risk of further melanomas. Your doctor may recommend taking a supplement.

## Protecting your skin from the sun

After a diagnosis of melanoma, you should check your skin regularly and follow SunSmart behaviour. When UV levels are 3 or above, use a combination of measures to protect your skin.

### Check sun protection times every day

Check the sun protection times for your local area through the 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 with a free website widget.

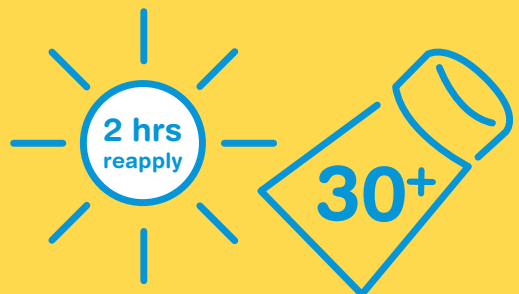


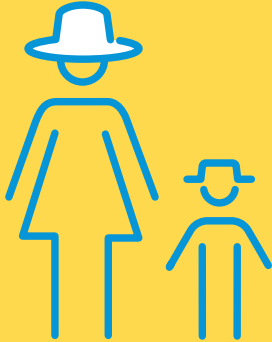
### Slip on clothing

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

### 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. 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. Adult hats should have at least a 7.5 cm brim.



### Slide on sunglasses

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

### 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 through the shade, even if the direct sun is blocked, the shade will not completely protect you from UV.



### Protect children

Use a combination of sun protection measures to protect babies and children from direct exposure to sunlight. Applying sunscreen on babies under 6 months is not recommended.

### Avoid sun lamps and solariums

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

## What if the melanoma returns?

In the vast majority of cases, early melanoma will not come back (recur) after treatment. The risk of the melanoma coming back after treatment is higher for people with regional melanoma. Recurrence can occur at the site where the melanoma was removed (locally); 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 their age. It is important to be familiar with your skin, examine it for changes, and visit your doctor for regular check-ups.

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

If the cancer returns, your doctor will discuss the treatment options with you. These will depend on where the cancer has recurred, as well as the stage and grade of the cancer. You may be offered immunotherapy, targeted therapy or the option to join a clinical trial.





## Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ 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

## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

### Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



### Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

### Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



### Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

### Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).



## Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian	
Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carers Australia	<a href="http://carersaustralia.com.au">carersaustralia.com.au</a>
Department of Human Services	<a href="http://humanservices.gov.au">humanservices.gov.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Optimal Care Pathways	<a href="http://cancerpathways.org.au">cancerpathways.org.au</a>
Australia and New Zealand Melanoma Trials Group	<a href="http://anzmtg.org">anzmtg.org</a>
Melanoma Institute Australia	<a href="http://melanoma.org.au">melanoma.org.au</a>
Melanoma Patients Australia	<a href="http://melanomapatients.org.au">melanomapatients.org.au</a>
Melanoma WA	<a href="http://melanomawa.org.au">melanomawa.org.au</a>
Skin & Cancer Foundation Inc	<a href="http://skincancer.asn.au">skincancer.asn.au</a>
SunSmart	<a href="http://sunsmart.com.au">sunsmart.com.au</a>
International	
American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
Macmillan Cancer Support (UK)	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
Melanoma Research Foundation (US)	<a href="http://melanoma.org">melanoma.org</a>
Skin Cancer Foundation (US)	<a href="http://skincancer.org">skincancer.org</a>



# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

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

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Associations** – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

➤ See our *Caring for Someone with Cancer* booklet.



# Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

## Diagnosis

- 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?

## Treatment

- What treatment do you recommend? What is the aim of the treatment?
- 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?

## Side effects

- 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?

## After treatment

- How often will I need to 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 get enough vitamin D and not get too much sun?
- If the melanoma returns, how will I know? What treatments could I have?



# Glossary

## **ABCDE criteria**

A set of signs used to help identify melanoma. The letters stand for: A=Asymmetry, B=Border, C=Colour, D=Diameter and E=Elevation.

## **acral lentiginous melanoma**

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

## **adjuvant treatment**

A treatment given with or shortly after the main treatment to enhance the main treatment's effectiveness.

## **advanced melanoma**

Cancer that is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

## **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 temporary loss of consciousness.

## **basal cell**

One of the three types of cells that make up the epidermis of the skin.

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

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

## **benign**

Not cancerous or malignant.

## **biopsy**

The removal of a sample of tissue for examination under a microscope.

## **BRAF gene mutation**

A non-inherited gene change which can tell cancer cells to multiply.

## **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.

## **checkpoint immunotherapy**

Drugs that work by allowing the immune system to pass "checkpoints" set up by the cancer to block the immune system.

## **chemotherapy**

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

## **Clark level**

A number (I–V) that describes how deeply a melanoma has penetrated into the skin.

## **clinical trial**

A research study that tests new approaches to prevention, screening, diagnosis or treatment, to see if they are better than current approaches.

## **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**

A rare type of melanoma of the skin.

## **dysplastic naevus (plural: naevi)**

A mole with an irregular shape and uneven colour.

**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.

**fine needle biopsy**

The removal of a tissue sample with a fine needle for examination under a microscope. Also called a fine needle aspiration.

**genes**

The microscopic units that determine how the body's cells grow and behave.

**immunotherapy**

Treatment that uses the body's own immune system to fight cancer.

**intravenous (IV)**

Injected into a vein.

**lentigo maligna melanoma**

A type of melanoma of the skin that starts as a large freckle (lentigo maligna).

**lesion**

An area of abnormal tissue.

**localised melanoma**

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

**lymphatic system**

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells. Includes spleen and lymph nodes.

**lymph node dissection**

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

**lymph nodes**

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

**lymphocele**

See seroma.

**lymphoedema**

Swelling caused by a build-up of lymph fluid. Can develop in the neck, arm or leg.

**lymph vessels**

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

**malignant**

Cancerous.

**margin**

The edge of tissue removed during surgery. Clear or negative margin means no cancer cells were found on the edge of the removed tissue. Positive margin means cancer cells were found on the edge of the removed tissue.

**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. Usually appears on the skin but may affect the eye, mucous membrane (the moist lining of the mouth, digestive tract, etc.) or the nervous system.

**melanoma in situ**

An early melanoma that is confined to the upper layer of the skin (epidermis).

**metastasis (plural: metastases)**

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

**mitotic rate**

Measures how quickly the melanoma cells divide.

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

**non-melanoma skin cancer**

Skin cancer that doesn't develop from melanocyte cells, e.g. basal cell cancer 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 scan in which a person is injected with a small amount of radioactive glucose solution to find cancerous areas.

**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.

**radiation therapy**

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

**recurrence**

The return of a disease after a period of improvement (remission).

**regional melanoma**

Melanoma that has spread to the lymph nodes.

**regression**

An area within a melanoma where melanoma cells have been destroyed and replaced by scar tissue.

**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. Also called lymphocele.



### 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

One of the three types of cells that make 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 melanoma of the skin, making up 55–60% of all cases.

### systemic treatment

Treatment that affects the whole body.

### targeted therapy

Drugs that attack specific particles (molecules) within cells that allow cancer to grow and spread.

### tissue

A collection of cells of similar type 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).

### ulceration

The breakdown or loss of the outer layer of skin.

### 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 international 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. Cancer Council Australia Melanoma Guidelines Working Party, *Clinical practice guidelines for the diagnosis and management of melanoma*, Cancer Council Australia, Sydney, 2018. [Cited 20 September 2018]. Available from: [wiki.cancer.org.au/australia/Guidelines:Melanoma](http://wiki.cancer.org.au/australia/Guidelines:Melanoma).
2. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: melanoma of the skin*, AIHW, Canberra, December 2017.



## 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 other Pink events, 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.

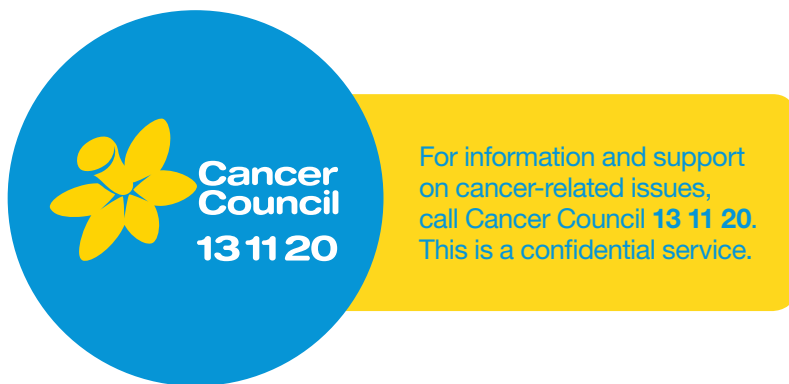
Cancer Council services and programs vary in each area.

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, you can 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

**Cancer Council Victoria**  
cancervic.org.au

**Cancer Council WA**  
cancerwa.asn.au

**Cancer Council Australia**  
cancer.org.au

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