

# Understanding Melanoma

*A guide for people with cancer, their families and friends*



For information & support, call **13 11 20**

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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 or keratinocyte 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. 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, 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 Australian clinical practice guidelines.<sup>1</sup>



If you or your family have any questions or concerns, 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).

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### **Key to icons**

Icons are used throughout this booklet to indicate:



More information



Alert



Personal story

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# What is cancer?

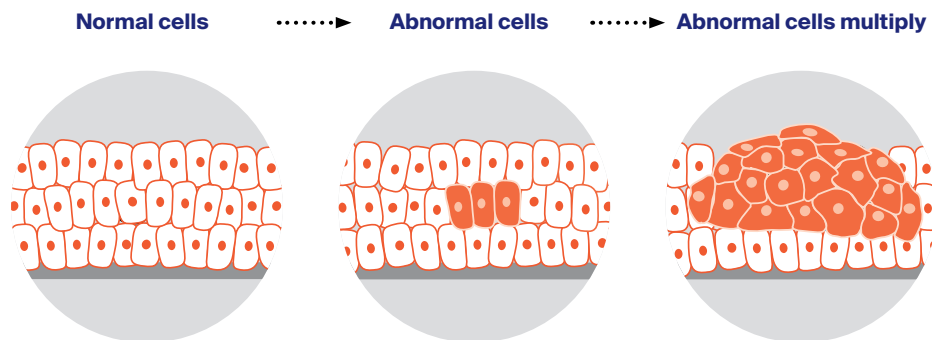
Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

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. These abnormal cells may turn into cancer.

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.

## How cancer starts

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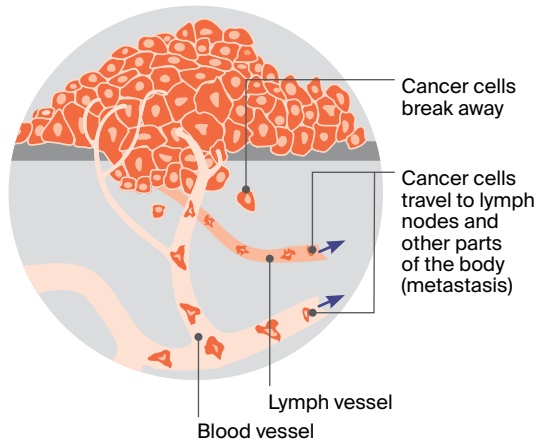
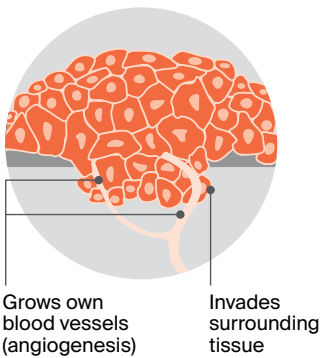


Not all tumours are cancers. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops 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



# 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. 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.

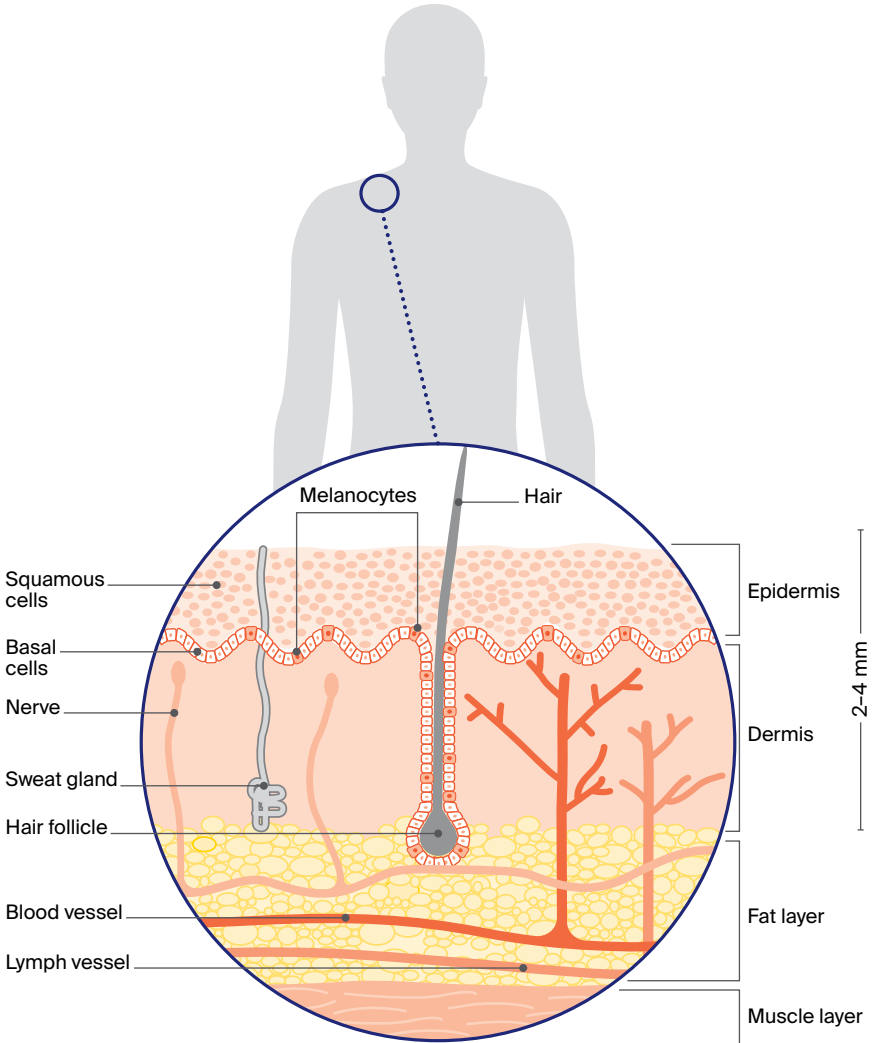
**Melanocytes** – These cells sit between the basal cells and produce a dark pigment called melanin, the substance that gives skin its colour. When skin is exposed to ultraviolet (UV) radiation, melanocytes make extra melanin to try to protect the skin from getting burnt. This is what causes skin to 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 hair roots (follicles), sweat glands, blood vessels, lymph vessels and nerves.



# The layers of the skin

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# Key questions

## Q: What is melanoma?

**A:** Melanoma is a type of skin cancer. It develops in the skin cells called melanocytes (see page 6) and usually occurs on parts of the body that have been overexposed to the sun.

Rarely, 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 mucous membranes (e.g. sinuses, digestive tract, genitals), the soles of the feet or palms of the hands, and under the nails.

Other types of skin cancer include basal cell carcinoma (BCC) and squamous cell carcinoma (SCC). These are known as non-melanoma skin cancers or keratinocyte cancers, and they are far more common than melanoma. However, melanoma is considered the most serious form of skin cancer because it is more likely to spread to other parts of the body, especially if not found 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. Every year, about 16,000 people are diagnosed with melanoma in Australia.

Melanoma is the second most common cancer in men and the third most common cancer in women (excluding non-melanoma skin cancers).<sup>2</sup>

## Q: What are the signs and symptoms?

**A:** How melanoma looks can vary greatly. If you have lots of moles, a melanoma usually stands out and looks different from other moles. The first sign is often a new spot or a change in an existing mole:

- **size** – the spot may appear, or begin to grow larger
- **colour** – the spot may become blotchy with different depths and shades of colour (often brown or black, but about 20% of melanomas are “amelanotic” and appear as red, white, light grey, pink or the colour of your skin)
- **shape or border** – the spot may increase in height, become scaly, have an irregular shape (scalloped or notched) or not be symmetrical (the halves may look different)
- **itching or bleeding** – the spot may itch or bleed very easily
- **elevation** – the spot may start as a raised nodule or develop a raised area, which is often reddish or reddish brown.

New moles mostly appear during childhood and through to the 30s and 40s, as well as during pregnancy. However, adults of any age can have new or changing spots. It is important to get to know your skin and check it regularly. In a room with good light, fully undress and use a full-length mirror to check your whole body. For areas that are hard to see, use a handheld mirror or ask someone to help.

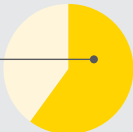
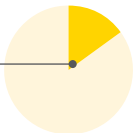
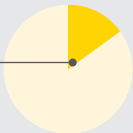


Look for spots that are new, different from other spots, or raised, firm and growing. Even if your doctor has said a spot is benign in the past, check for any changes in shape, size or colour. If you notice a new or changing spot, ask your doctor to examine it.



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

## What are the main types of melanoma?

Melanoma of the skin is known as cutaneous melanoma. The main subtypes of cutaneous melanoma are shown in this table. Some rarer types of melanoma start in other parts of the body. Mucosal melanoma can start in the tissues in the mouth,

Subtype	How common?	Who gets it?
<b>superficial spreading melanoma</b>	<b>55–60%</b> of melanomas 	most common type of melanoma in people under 40, but can occur at any age
<b>nodular melanoma</b>	<b>10–15%</b> of melanomas 	most commonly found in people over 65
<b>lentigo maligna melanoma</b>	<b>10–15%</b> of melanomas 	most people with this subtype are over 40
<b>acral lentiginous melanoma</b>	<b>1–2%</b> of melanomas 	mostly affects people over 40
<b>desmoplastic melanoma</b>	<b>1–2%</b> of melanomas 	mostly affects people over 60

anus, urethra, vagina or nasal passages. Ocular melanoma can start inside the eye. Melanoma can also start in the central nervous system. Call Cancer Council 13 11 20 for information about rarer types of melanoma.

<b>What does it look like?</b>	<b>Where is it found?</b>	<b>How does it grow?</b>
can start as a new brown or black spot that grows on the skin, or as an existing spot, freckle or mole that changes size, colour or shape	can develop on any part of the body but especially the trunk	often grows slowly and becomes more dangerous when it invades the lower layer of the skin (dermis)
usually appears as a round, raised lump (nodule) on the skin that is pink, red, brown or black and feels firm to touch; may develop a crusty surface that bleeds easily	usually found on sun-damaged skin on the head and neck	fast-growing form of melanoma, spreading quickly into the lower layer of the skin (dermis)
begins as a large coloured spot (lentigo maligna)	mostly found on sun-damaged skin on the face, ears, neck or head	may grow slowly and superficially over many years before it grows deeper into the skin
often appears as a colourless or lightly coloured area, may be mistaken for a stain, bruise or unusual wart; in the nails, can look like a long streak of pigment	most commonly found on the palms of the hands or on the soles of the feet, or under the fingernails or toenails	tends to grow slowly until it invades the lower layer of the skin (dermis)
starts as a firm, growing lump, often the same colour as your skin; may be mistaken for a scar and can be difficult to diagnose	mostly found on sun-damaged skin on the head or neck	tends to be slower to spread than other subtypes, but often diagnosed later



For an overview of what to expect at every stage 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.

## Q: What causes melanoma?

**A:** The main cause of all types of skin cancer is overexposure to ultraviolet (UV) radiation.

UV radiation most often comes from the sun, but it can also come from artificial sources such as solariums (also known as tanning beds or sun lamps). Solariums are now banned for commercial use in Australia because research shows that people who use solariums have a much greater risk of developing melanoma.

Anyone can develop melanoma. The risk is higher in people who have:

- unprotected exposure to UV radiation, particularly a pattern of short, intense periods of sun exposure and sunburn, such as on weekends and holidays
- lots of moles (naevi) – more than 10 moles above the elbow on the arms and more than 50 on the body, especially if the moles have an irregular shape and uneven colour (dysplastic naevi)
- pale, fair or freckled skin, especially if it burns easily and doesn't tan
- light-coloured eyes (blue or green), and fair or red hair
- a previous melanoma or other type of skin cancer
- a strong family history of melanoma (see opposite)
- a weakened immune system from using immunosuppressive medicines for a long time (e.g. for rheumatoid arthritis or another autoimmune disease or after an organ transplant).

## Q: Why is sun protection important?

**A:** When your unprotected skin is exposed to the sun or other UV radiation, the structure and behaviour of the cells can change. This can permanently damage the skin, and the damage adds up over time.

Being exposed to too much UV radiation as a child increases the risk of skin cancer later in life, although sun protection will help prevent melanoma at any age. See pages 42–44 for more information about protecting your skin from overexposure to the sun and sun damage.

## Family history of melanoma

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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.

If two or more close relatives (parent, sibling or child) have been diagnosed with melanoma, they may have an inherited faulty gene. This is especially the case if they are diagnosed with more than one melanoma on different areas of the

skin, or if they are diagnosed with melanoma before the age of 40.

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 or skin spots 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:** You will probably start by seeing your general practitioner (GP). Some people choose to go to skin cancer clinics, which are often operated by GPs with an interest in skin cancer.

If a GP diagnoses or suspects melanoma, they will usually refer you to a specialist, such as a dermatologist or surgeon. The specialist will arrange further tests and consider the 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 see a range of health professionals who specialise in different aspects of your care, especially if the melanoma has a Breslow thickness greater than 1 mm (see page 19) or if it has spread to other parts of the body.

### **Melanoma units**

Some people are treated in specialist melanoma units located at hospitals in major cities around Australia. Your GP is most likely to refer you to one of these units if the melanoma is considered high risk (based on the Breslow thickness, see page 19).

In a specialist melanoma unit, you will be able to talk to one or more medical specialists from the multidisciplinary team. They will answer your questions and recommend the most suitable treatment pathway based on your test results (see pages 16–22).

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



## Health professionals you may see

<b>GP</b>	checks skin for suspicious spots, may remove potential skin cancers and refer you to specialists
<b>dermatologist*</b>	diagnoses, treats and manages skin conditions, including skin cancer
<b>general surgeon*</b>	performs surgery to remove early melanoma and lymph nodes, and to reconstruct the skin
<b>reconstructive (plastic) surgeon*</b>	performs surgery that restores, repairs or reconstructs the body's appearance and function; may also remove lymph nodes
<b>surgical oncologist*</b>	performs surgery to remove melanoma and conducts more complex surgery on the lymph nodes and other organs; can be a general surgeon or a reconstructive surgeon
<b>medical oncologist*</b>	treats melanoma with drug therapies such as targeted therapy and immunotherapy
<b>radiation oncologist*</b>	plans and oversees 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 nurse</b>	work closely with the GP and cancer specialists to help control symptoms and maintain quality of life

\* *Specialist doctor*






# Diagnosis

The first step in diagnosing a melanoma is a close examination of the spot. If the spot looks suspicious, the doctor will remove it so it can be checked in a laboratory. In some cases, further tests will be arranged.

## Physical examination

If you notice any changed or suspicious spots, your doctor will look carefully at your skin. 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 spots more closely and consider the signs known as the ABCDE guidelines.

### ABCDE signs of melanoma

<b>Asymmetry</b>	Are the halves of each spot 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, or is it smaller than 6 mm but growing larger?	
<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 guidelines, so your doctor may also assess whether the spot is raised, firm or growing.

## Removing the spot (excision biopsy)

If the doctor suspects that a spot on your skin may be melanoma, the whole spot is removed (excision biopsy) so it can be examined by a specialist doctor called a pathologist.

An excision biopsy 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 the 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 of healthy tissue (2 mm margin) 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 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 26–28).

## Checking lymph nodes

Lymph nodes are part of your body's lymphatic system, which helps to protect the body against disease and infection. The lymphatic system is a network of vessels, tissues and organs. There are large groups of lymph nodes in the neck, armpits and groin. Sometimes melanoma can travel through the lymphatic system to other parts of the body.

To work out if the melanoma has spread, your doctor will feel the lymph nodes closest to the melanoma and may recommend an ultrasound (see page 20) and a fine needle biopsy or a sentinel lymph node biopsy.

**Fine needle biopsy** – If any lymph nodes feel enlarged or lumpy, you will probably have a fine needle biopsy. This uses a thin needle to take a sample of cells from the enlarged lymph node. The sample is then examined under a microscope to see if it contains cancer cells. If cancer is found in the lymph nodes, you may need to have surgery to remove them (lymph node dissection, see pages 30–31).

**Sentinel lymph node biopsy** – You may be offered a sentinel lymph node biopsy if the lymph nodes do not seem enlarged but the melanoma is considered high risk (based on the Breslow thickness, see opposite page). This biopsy finds and removes the first lymph node that the melanoma would be likely to spread to (the sentinel node). Sometimes more than one sentinel node is found and removed. The removed lymph nodes are then checked for melanoma cells under a microscope. A sentinel lymph node biopsy is usually done at the same time as the wide local excision (see pages 26–28).

To find the sentinel lymph node, a small amount of radioactive dye is injected into the area where the initial melanoma was found. The surgeon removes any lymph nodes that take up the dye so they can be checked for cancer cells. If cancer cells are found in a removed lymph node, you may have further tests such as CT or PET-CT scans (see page 20) and further treatment may be offered (see page 32). The results of a sentinel lymph node biopsy can help predict the risk of melanoma spreading to other parts of the body. This information helps your doctor plan your treatment. It may also allow you to take part in a new clinical trial (see page 25).

## Understanding the pathology report

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If you have a melanoma removed, the report from the pathologist will provide your treatment team with information to help work out how far the melanoma has spread (the stage), the recommended treatment plan and the expected outcome (prognosis).

You can ask your doctor for a copy of the pathology report 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 known as ulceration. It 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 on a scale of 1–5, with 1 the shallowest and 5 the deepest. (On the report, the Clark level will be written in Roman numerals as I, II, III, IV or V.) Breslow thickness is much more important than Clark level in working out the stage of a melanoma.

**Margin** – This is the area of normal skin around the melanoma. The report will describe how wide the margin is and whether any melanoma cells were found at the edge of the removed tissue.

**Regression** – This refers to inflammation or scar tissue in the melanoma, which suggests that some melanoma cells have been destroyed by the immune system. In the report, the presence of lymphocytes (immune cells) in the melanoma indicates inflammation.

## Further tests

Many people will need only a biopsy. Some people will have further tests such as blood tests or imaging scans to get more information about the melanoma. You may also have these tests during treatment or as part of follow-up care after treatment finishes. Imaging scans use different methods to create images of the inside of the body:

**Ultrasound** – The person doing the ultrasound will move a handheld device called a transducer across part of your body. The transducer sends out soundwaves that echo when they meet something solid, such as an organ or tumour. A computer turns the echoes into pictures.

**CT scan** – A CT (computerised tomography) scan uses x-ray beams to create detailed, cross-sectional pictures. Before the scan, you may have an injection of a liquid dye (called the contrast) to make the pictures clearer. The CT scanner is large and round like a doughnut. You will need to lie still on a table while the scanner moves around you.

**MRI scan** – An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to create detailed cross-sectional pictures. Before the scan, you may have an injection of a liquid dye (called the contrast) to make the pictures clearer. During the scan, you will lie on an examination table that slides into a large metal tube that is open at both ends. The scan can be noisy, but you will usually be offered headphones or earplugs.

**PET-CT scan** – A PET (positron emission tomography) scan combined with a CT scan is a specialised imaging test. You will be injected in the arm with a glucose solution containing a small amount of radioactive material. Cancer cells show up brighter on the scan because they take up more of the glucose solution than normal cells do.

## Staging melanoma

The pathology report and any other test results will show whether you have melanoma and whether it has spread to other parts of the body.

This is known as staging and it helps your team recommend the most appropriate treatment for you. The melanoma will be given an overall stage of 0–4 (usually written in Roman numerals as 0, I, II, III or IV).

### Stages of melanoma

<b>stage 0 (in situ)</b>	The melanoma is confined to the top, outer layer of the skin.	early or localised melanoma
<b>stage 1</b>	The melanoma has not moved beyond the primary site and is less than 1 mm thick with or without ulceration, or 1–2 mm thick without ulceration.	early or localised melanoma
<b>stage 2</b>	The melanoma has not moved beyond the primary site and is 1–2 mm thick and ulcerated, or more than 2 mm thick with or without ulceration.	early or localised melanoma
<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).	regional melanoma
<b>stage 4</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.	advanced or metastatic melanoma

## Gene mutation testing

If the melanoma has spread (stage 3 or 4), special 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.

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

Genetic tests can be done on the sample removed during surgery. The test results will help doctors work out whether particular drug therapies may be useful (see pages 35–37).

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for anyone to predict the exact course of the disease. Instead, your doctor can discuss any concerns you may 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 more deeply a melanoma grows 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 drug treatments that continue to improve the prognosis for people with melanoma that has spread from the primary site (advanced or metastatic melanoma).



## Key points about diagnosing melanoma

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### Main tests

Tests to diagnose melanoma include:

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

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### 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.

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### Staging and prognosis

The stage shows how far the melanoma has spread:

- early or localised melanoma is stages 0–2
- regional melanoma is stage 3
- advanced or metastatic melanoma is stage 4.

For stage 3 or 4, 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 melanoma.



# 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, as it may not 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 says you have cancer, you may not remember everything you are told. Taking notes can help, or you might like to ask if you can record the discussion. 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?

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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 0-2 or localised melanoma) can generally be treated successfully with surgery alone. If the melanoma has spread to nearby lymph nodes or tissues (stage 3 or regional melanoma), treatment may also include removal of lymph nodes and additional (adjuvant) treatments.

## Surgery (wide local excision)

Surgery to remove the mole is the main treatment for early melanoma, and is often the only treatment you need. Even though the excision biopsy to diagnose melanoma (see page 17) may remove the melanoma, a doctor or surgeon will usually recommend a second procedure known as a wide local excision. This means removing more normal-looking skin from around the melanoma (wider margin).

Removing more skin around the melanoma reduces the risk of it coming back (recurring) at that site. The recommended margin is usually between 5 mm and 10 mm, depending on the type, thickness and site of the melanoma. For thicker tumours, a wider margin of up to 20 mm may be advised.

A wide local excision is often performed as a day procedure. 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) performed at the same time as the wide local excision.

▶ 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 (most often 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 a number of factors, including:

- where the melanoma is
- how much tissue has been removed
- 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 a dressing on any area that had skin removed for the graft.



After a wide local excision, the tissue removed from around the melanoma will be sent to a laboratory for testing. If the edge of the tissue sample doesn't contain any cancer cells, it is called a clear margin. If the margins aren't clear, you may need further surgery to remove more tissue.

## What to expect after surgery

Most people recover quickly after a wide local excision to remove a melanoma, but you will need to keep the wound clean.

### 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.

### 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. In this case, you will need to have another procedure to create a new flap or graft.

### 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.

### When to seek advice



Talk to your doctor if you have any unexpected bleeding, bruising, infection, scarring or numbness after surgery.



## 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 1960s 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. 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 asked 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 found the whole experience rattled me a bit. I'm thankful the melanoma was found early and my treatment was so straightforward.*

***“I did suspect that it might be a melanoma, but I was still shocked when this was confirmed.”***

## Removing lymph nodes

Many people with early melanoma will not need to have any lymph nodes removed.

In some cases, you may have a sentinel lymph node biopsy (see page 18) at the same time as the wide local excision. This removes the first lymph node that melanoma may have spread to. If melanoma is found in the removed node, you will need to have regular imaging scans to check that the melanoma has not come back or spread. You may also be offered drug therapy (see page 32) to reduce the risk of the melanoma returning.

Occasionally, melanoma may spread to lymph nodes and cause lumps that your doctor can feel during a physical examination. If a fine needle biopsy (see page 18) confirms that a lymph node contains melanoma, that group of lymph nodes may 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.

## Side effects of lymph node removal

Having your lymph nodes removed can cause side effects. These are likely to be milder if you have only a few lymph nodes removed.

**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 ask your GP or cancer care team to refer you to a physiotherapist.

**Seroma/lymphocele** – This is a collection of fluid in the area where the lymph nodes have been removed. It is a common side effect and appears straight after surgery. It usually gets better after a few weeks, but sometimes your surgeon may drain the fluid with a needle.

**Lymphoedema** – This is a swelling of the neck, arm or leg that may appear after lymph node removal (see below).

## Managing lymphoedema

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If treatment for melanoma removes or damages lymph nodes, your neck, arm or leg may later become swollen. 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.

Your risk of developing lymphoedema following melanoma treatment depends on the extent of the surgery and whether you've had radiation therapy (see pages 37–38) that has damaged the lymphatic system.

Lymphoedema can develop a few weeks, or even several years, after treatment. Although this condition

may be permanent, it can usually be managed, especially if treated at the earliest sign of swelling or heaviness.

A lymphoedema practitioner can help you manage lymphoedema. To find a practitioner, visit [lymphoedema.org.au](http://lymphoedema.org.au) or ask your doctor for a referral. You may need to wear a professionally fitted compression garment. Massage and regular exercise, such as swimming, cycling or yoga, can help the lymph fluid flow. It is also important to keep the skin healthy and unbroken to reduce the risk of infection.

▶ See our *Understanding Lymphoedema* fact sheet.

## Further treatment after surgery

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 use drugs that enter the bloodstream and travel throughout the body. This is known as systemic treatment.

The main systemic treatments for melanoma are:

- **immunotherapy** – drugs that use the body's own 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.

Chemotherapy is another form of systemic drug treatment. It is used to treat many cancers, but it is rarely used for melanoma because immunotherapy and targeted therapy drugs usually work better.

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

For further information about immunotherapy, targeted therapy and radiation therapy, see the *Treatment for advanced melanoma* chapter on pages 34–39. You may also be offered an opportunity to participate in a clinical trial (see page 25).

## Key points about treating early melanoma

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### What it is

Melanoma is a type of skin cancer. Early or localised melanoma has not spread outside the primary site. Regional melanoma has spread to nearby lymph nodes, skin or tissue.

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### The main treatment

The main treatment is surgery to remove the suspicious area. Surgery for melanoma may include:

- wide local excision – cuts out extra skin around the melanoma (wider margin)
  - sentinel lymph node biopsy – removes the first lymph nodes that a melanoma may have spread to
  - lymph node dissection or lymphadenectomy – removes lymph nodes if melanoma has spread to them and caused lumps.
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### Further treatments

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

- immunotherapy – drugs that use the body's own immune system to fight melanoma
  - targeted therapy – drugs that attack specific features of cancer cells to stop the melanoma growing and spreading
  - radiation therapy – use of targeted radiation to damage melanoma cells in a specific area.
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# Treatment for advanced melanoma

When melanoma has spread to distant lymph nodes or other internal organs or bones (stage 4), it is known as advanced or metastatic melanoma. Treatment may include surgery, immunotherapy, targeted therapy and radiation therapy. Palliative treatment may also be offered to help manage 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, so it is best to have your treatment in a specialist melanoma unit (see page 14). You will be offered a treatment plan based on factors such as the features of the melanoma, where it has spread and any symptoms you have. New developments are occurring all the time, and you may be able to access new treatments through clinical trials (see page 25).

## Surgery

In some cases, surgery may be recommended for people with advanced melanoma. It is used to remove melanoma from the skin (see pages 26–28), lymph nodes (see pages 30–31), or other organs such as the lung or brain. Your suitability for surgery will be discussed at a multidisciplinary team meeting (see page 14).

Talk to your treatment team about what the surgery involves and what recovery will be like. Side effects will depend on the type of surgery, but often include pain and risk of infection (see pages 28 and 30–31).

▶ See our *Understanding Surgery* booklet.

## Immunotherapy

Immunotherapy drugs called checkpoint inhibitors use the body's own immune system to fight cancer. They have led to great progress in melanoma treatment. Checkpoint inhibitors used for advanced melanoma include ipilimumab, nivolumab and pembrolizumab.

You will usually have checkpoint immunotherapy as an outpatient, which means you visit the treatment centre for the day. In most cases, the drugs are given into a vein (intravenously). You may have treatment every 2–4 weeks in a repeating cycle for up to two years, but this depends on how the melanoma responds to the drugs and any side effects you have.

Checkpoint inhibitors do not work for everyone with advanced melanoma, but some people have had very encouraging results. Sometimes more than one drug is used, and different combinations work for different people. Treatments in this area are changing rapidly. Talk to your doctor about whether immunotherapy is an option for you.

*“Every three weeks, I’d go to the treatment centre for an immunotherapy infusion. I had very few side effects, I was really lucky. I did get a tiny bit of a rash and I got pretty tired after each infusion, but I’d just go and have a snooze.”* IAN

### Side effects of immunotherapy

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

skin problems. The inflammation can lead to more serious side effects in some people, but this will be monitored closely and managed quickly.

You may have side effects within days of starting immunotherapy, but more often they occur many weeks or months later. It is important to discuss any side effects with your treatment team as soon as they appear so they can be managed appropriately. When side effects are treated early, they are likely to be less severe and last for a shorter time.

▶ See our *Understanding Immunotherapy* fact sheet.



It is important to let your doctor know immediately of any side effects from immunotherapy or targeted therapy treatment. If left untreated, some side effects can become serious.

## Targeted therapy

New types of drugs known as targeted therapy attack specific genetic mutations within cancer cells (see page 22), while trying to limit harm to healthy cells. They are generally taken as tablets (orally) once or twice a day, often for many months or even years.

Several targeted therapy drugs are used for melanoma with the BRAF mutation. Different drugs may be given together to help reduce the growth of the melanoma and minimise side effects – for example, dabrafenib is often used with trametinib. Drugs for NRAS and C-KIT mutations may be available through clinical trials – talk to your doctor about whether one of these trials is right for you.

Cancer cells can become resistant to targeted therapy drugs over time. If this happens, your doctor may suggest trying another targeted therapy drug or another type of treatment.

## 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, joint pain, rash and other skin problems, loss of appetite, nausea and diarrhoea.

Ask your treatment team for advice about dealing with any side effects.

► See our *Understanding Targeted Therapy* fact sheet.

## Radiation therapy

Also known as radiotherapy, radiation therapy is the use of targeted radiation, such as x-ray beams, to kill or damage cancer cells. Radiation therapy may be offered on its own or with other treatments. In rare cases, it is used after surgery to prevent melanoma coming back. It can also help relieve pain and other symptoms caused by melanoma that has spread to the brain or bone (palliative treatment, see next page).

Before starting treatment, you will have a CT or MRI scan at a planning appointment. The technician may make some small permanent or temporary marks on your skin so that the same area is targeted during each treatment session.

Treatment sessions are usually given daily over 1–4 weeks. The number of sessions will depend on the size and location of the tumour, and your general health. For the treatment, you will lie on a table under a machine that aims radiation at the affected part of your body. Each session takes about 20–30 minutes and is painless.

In some cases, you may be offered a specialised type of treatment that delivers tightly focused beams of high-dose radiation onto the tumour from many different angles. This is called stereotactic radiosurgery (SRS) when used on the brain, and stereotactic body

radiation therapy (SBRT) when used on other parts of the body. 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 have treatment. Many people will have temporary side effects, which may build up over time. Common side effects include tiredness and skin in the treatment area becoming red and sore during or immediately after radiation therapy. Ask your treatment team for advice about dealing with any side effects.

▶ See our *Understanding Radiation Therapy* booklet.

## Palliative treatment

In some cases of advanced melanoma, the medical team may talk to you about palliative treatment. Palliative treatment aims to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It can be used at any stage of advanced cancer and does not mean giving up hope. Some people have palliative treatment as well as active treatment of the melanoma.

When used as palliative treatment, radiation therapy and medicines can help manage symptoms caused by advanced melanoma, such as pain, nausea and shortness of breath.

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

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



## Key points about treating advanced melanoma

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### What it is

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

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### Treatments

Treatment options for advanced melanoma depend on where the cancer has spread to, various test results and whether the cancer has a particular gene mutation. Treatments may include:

- surgery – removes melanoma from the skin, lymph nodes or organs
  - immunotherapy – uses drugs to help the body's immune system recognise and fight melanoma
  - targeted therapy – uses drugs that attack specific features of melanoma cells
  - radiation therapy – uses targeted radiation to damage melanoma cells
  - palliative treatment – seeks to improve quality of life without aiming to cure the cancer.
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### Side effects

- Surgery can cause pain, risk of infection and other side effects.
  - Immunotherapy drugs can cause inflammation of any organ in the body. Common side effects include joint pain, diarrhoea and skin rash.
  - Targeted therapy can cause fever, tiredness, joint pain, skin rash and other side effects.
  - Radiation therapy may cause tiredness and skin reactions.
-

# 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, may prevent successful treatment of the cancer and can be harmful. 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 whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▶ 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. The experience of having cancer 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 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.

## Protecting your skin

Most melanomas are caused by exposure to the sun's UV radiation. After a diagnosis of melanoma, it is especially important to check 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 (UPF) rating, and darker fabrics where possible.

### 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; hats for children aged 8–12 should have at least a 6 cm brim.

### Slop on sunscreen



Use an SPF 30 or higher broad-spectrum water-resistant sunscreen. Apply 20 minutes before going out and reapply every two hours, or after swimming, sweating or any activity that causes you to rub it off. For an adult, the recommended amount is 1 teaspoon for each arm, each leg, front of body, back of body, and the face, neck and ears – a total of 7 teaspoons of sunscreen for one application.

### Slide on sunglasses



Protect your eyes with sunglasses that meet the Australian Standard AS/NZS 1067. Wraparound styles are best. Sunglasses should be worn all year round to protect both the eyes and the delicate skin around the eyes.

regularly (see page 9) and follow SunSmart behaviour. When UV levels are 3 or above, use a combination of the following measures to protect your skin.

## 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, so shade should never be the only form of sun protection used. 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.

## Avoid solariums



Do not use solariums. Also known as tanning beds or sun lamps, solariums give off artificial UV radiation and are banned for commercial use in Australia.

## Check daily sun protection times



Use the SunSmart UV Alert to check the recommended sun protection times in your local area every day.

It is available as an 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.

## Understanding sun protection

If you have been diagnosed with melanoma, you need to take special care to protect your skin from the sun's UV radiation. This will reduce your risk of further melanomas.

The UV Index shows the intensity of the sun's UV radiation. It can help you work out when to use sun protection. An index of 3 or above indicates that UV levels are high enough to damage unprotected skin, so sun protection is recommended. The recommended daily sun protection times (see previous page) are when UV levels are forecast to be 3 or higher. These will vary according to where you live and the time of year.

## 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 body can absorb only 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. Most people reach adequate vitamin D levels through incidental exposure to the sun. When the the UV Index is 3 or above, this may mean spending just a few minutes outdoors on most days of the week.

Getting too much UV is not recommended, even for people with too little vitamin D (vitamin D deficiency). After a melanoma diagnosis, you will be at higher risk of further melanomas, and your doctor may advise you to limit your sun exposure as much as possible. In some cases, this may mean you don't get enough sun exposure to maintain your vitamin D levels. If you are concerned about vitamin D deficiency, talk to your doctor about how to get enough vitamin D while reducing your risk of further melanomas. Your doctor may advise you to take a supplement.

# 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 melanoma, 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

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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, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue 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

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 (see page 9) and go to your follow-up appointments. At these follow-up appointments, your doctor will examine the area that was treated and your lymph nodes to check that the melanoma hasn't come back or spread. Your doctor will also check the rest of your skin for any new melanomas.

The follow-up plan will vary depending on the stage – more frequent visits are recommended for people with advanced melanoma. Your doctor can give you more details of your follow-up plan. When a follow-up appointment or test is approaching, many people 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.

## What if the melanoma returns?

For most people, early melanoma will not come back (recur) after treatment. The risk of the melanoma returning 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, such as the lung, liver or brain.

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
- 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.



Surgery for melanoma often leaves a scar, which will usually fade with time. You may worry about how the scar looks, especially if it's on your face. Various cosmetics, hairstyles and clothing can help cover scarring. Look Good Feel Better is a national program that helps people manage the appearance-related effects of cancer treatment. For information about workshops in your area, call 1800 650 960 or visit [lgfb.org.au](http://lgfb.org.au).

## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

### 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 more than 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.

### 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.

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

### 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.

### Australia

Cancer Council Australia	<a href="https://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="https://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="https://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Cancer Australia	<a href="https://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carer Gateway	<a href="https://carergateway.gov.au">carergateway.gov.au</a>
Healthdirect Australia	<a href="https://healthdirect.gov.au">healthdirect.gov.au</a>
Melanoma and Skin Cancer Trials	<a href="https://masc.org.au">masc.org.au</a>
Melanoma Institute Australia	<a href="https://melanoma.org.au">melanoma.org.au</a>
Melanoma Patients Australia (including the Melanoma Nurse Telehealth Service)	<a href="https://melanomapatients.org.au">melanomapatients.org.au</a>
Melanoma WA	<a href="https://melanomawa.org.au">melanomawa.org.au</a>
Optimal Care Pathways	<a href="https://cancerpathways.org.au">cancerpathways.org.au</a>
Services Australia (including Medicare and Centrelink)	<a href="https://servicesaustralia.gov.au">servicesaustralia.gov.au</a>
Skin Health Institute	<a href="https://skinhealthinstitute.org.au">skinhealthinstitute.org.au</a>
SunSmart	<a href="https://sunsmart.com.au">sunsmart.com.au</a>

### International

American Cancer Society	<a href="https://cancer.org">cancer.org</a>
Cancer Research UK	<a href="https://cancerresearchuk.org">cancerresearchuk.org</a>
Macmillan Cancer Support (UK)	<a href="https://macmillan.org.uk">macmillan.org.uk</a>
Melanoma Research Foundation (US)	<a href="https://melanoma.org">melanoma.org</a>
Skin Cancer Foundation (US)	<a href="https://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 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 Australia** – Carers Australia provides information and advocacy for carers. 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

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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.

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## 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?
  - Are the latest tests and treatments for melanoma available in this hospital?
  - Can you explain the results of the tests to me?
  - Are there clinical guidelines for this type of cancer?
- 

## Treatment

- What treatment do you recommend? What is the aim of the treatment?
  - How long will treatment take? Will I have to stay in hospital?
  - How much will treatment cost? Can the cost be reduced if I can't afford it?
  - How will I know if the treatment is working?
  - Are there any clinical trials or research studies I could join?
- 

## Side effects

- What are the risks and possible side effects of each treatment? How can these be managed?
  - Will I have a lot of pain? If I do, what will be done about this?
  - Will there be any scarring after the melanoma is removed?
  - What are the chances I will get lymphoedema after treatment?
- 

## After treatment

- How often will I need to get my skin checked after treatment? Who should I go to for my skin checks?
  - How can I protect myself from the sun and get enough vitamin D?
  - If the melanoma returns, how will I know? What treatments could I have?
  - Are there any local support groups for people with melanoma?
-

# Glossary

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## **ABCDE guidelines**

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

## **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 after the main treatment to lower the risk that the cancer will come back (recur).

## **advanced melanoma**

Melanoma that has spread to other parts of the body. Also known as 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.

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## **basal cell**

One of the three types of cells that make up the top layer of the skin (epidermis).

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

A type of skin cancer that begins in the basal cells in the top layer of the skin. See also non-melanoma skin cancer.

## **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 that 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.

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## **cells**

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

## **checkpoint immunotherapy**

The use of drugs that work by helping the immune system to attack the cancer.

## **chemotherapy**

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

## **Clark level**

A number (1–5) that describes how many layers of skin a melanoma has gone through.

## **clinical trial**

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

## **C-KIT mutation**

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

## **CT scan**

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

## **cutaneous melanoma**

Melanoma that starts in the skin.

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## **dermis**

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

## **desmoplastic melanoma**

A rare type of melanoma of the skin. May be mistaken for a scar.

**dysplastic naevus (plural: naevi)**

A mole with an irregular shape and uneven colour.

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**epidermis**

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

**excision biopsy**

A type of biopsy where an area of abnormal tissue is surgically removed (excised).

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**fine needle biopsy**

The removal of a tissue sample with a fine needle. Also called a fine needle aspiration.

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**genes**

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

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**immunotherapy**

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

**intravenous (IV)**

Injected into a vein.

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**keratinocyte cancer**

See non-melanoma skin cancer.

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**lentigo maligna melanoma**

A type of melanoma of the skin that starts as a large coloured spot (lentigo maligna). It makes up about 10–15% of melanomas.

**lesion**

An area of abnormal tissue.

**localised melanoma**

A melanoma that has not spread from its original site to lymph nodes or other organs in the body. Also known as early melanoma.

**lymphatic system**

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces

immune cells. Includes the bone marrow, spleen, thymus 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 found in groups throughout the body. They help protect the body against disease and infection. 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 clear fluid known as lymph all over the body.

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**malignant**

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

**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 tissue.

**melanin**

Dark pigment produced in melanocytes that gives skin its colour.

**melanocyte**

One of the three types of cells that make up the top layer of the skin (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 top 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**

A measure of how quickly the melanoma cells divide.

### **mole**

See naevus.

### **mucosal melanoma**

A rare type of melanoma that starts in the tissues of the mouth, anus, urethra, vagina or nasal passages.

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### **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. It makes up about 10–15% of melanomas and is often fast growing.

### **non-melanoma skin cancer**

Skin cancer that doesn't develop from melanocyte cells, e.g. basal cell cancer (BCC) or squamous cell cancer (SCC). Also known as keratinocyte cancer.

### **NRAS gene mutation**

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

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### **ocular melanoma**

A rare type of melanoma that starts in the eye.

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### **palliative treatment**

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms.

### **PET-CT scan**

Positron emission tomography scan combined with CT scan. In a PET scan, you are injected with a small amount of radioactive glucose solution. This makes cancerous areas show up brighter on 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 expected outcome of a particular person's disease.

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### **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 from its original site to nearby lymph nodes or tissues.

### **regression**

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

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### **sentinel lymph node biopsy**

A surgical procedure used to determine whether a melanoma has spread from the primary site to the lymphatic system. The results can help with treatment planning.

### **sentinel node**

The first lymph node that melanoma is likely to spread to from the original site.



### **seroma**

A collection of fluid under a wound after an operation. Also called a lymphocele.

### **skin flap**

A procedure where nearby skin or fatty tissue is pulled over the wound left by the removal of a melanoma and stitched.

### **skin graft**

A procedure where a layer of skin is removed from one part of the body and fixed 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 skin (epidermis).

### **squamous cell carcinoma (SCC)**

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

### **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. It often grows slowly.

### **systemic treatment**

Treatment that affects the whole body.

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### **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 an organ or structure in the body.

### **trunk**

The central part of the body, not including the head, neck, arms and legs.

### **tumour**

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

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### **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 (also called tanning beds or sun lamps). UV radiation cannot be seen or felt.

### **UV Index**

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

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### **wide local excision**

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

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### **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)

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## **References**

1. Cancer Council Australia Melanoma Guidelines Working Party, *Clinical practice guidelines for the diagnosis and management of melanoma*, Cancer Council Australia, Sydney, viewed 22 July 2020, 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), *Cancer Data in Australia*, AIHW, Canberra, 2020, viewed 22 July 2020, available from [aihw.gov.au/reports/cancer/cancer-data-in-australia](http://aihw.gov.au/reports/cancer/cancer-data-in-australia).



# 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.



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. [communications.gov.au/accesshub/nrs](https://communications.gov.au/accesshub/nrs)

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

For information & support  
on cancer-related issues,  
call **Cancer Council 13 11 20**

## Visit your local Cancer Council website

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**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council NT**  
[nt.cancer.org.au](http://nt.cancer.org.au)

**Cancer Council Tasmania**  
[cancertas.org.au](http://cancertas.org.au)

**Cancer Council Australia**  
[cancer.org.au](http://cancer.org.au)

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*

