



# Your Guide

## Stage III Melanoma

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The contents of this book are personal and confidential.

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# The purpose of this guide

A melanoma diagnosis can be a confusing time for you and your loved ones. We have designed this guide to empower you with knowledge to support you at this challenging time.

This guide provides general information to help answer your questions about Stage III melanoma. You can use it to understand a bit more about your treatment and care. This guide also points you in the direction of other information or resources, should you need them.

It is hoped that you will find this guide a useful way to:

- keep important information in one place
- provide some questions to begin conversations with your health professionals
- assist you in recalling the information you are given
- provide a record of your care and the things you think are important
- prepare for follow up and the future.

## Who is this guide for?

If you or anyone you know has been diagnosed with Stage III melanoma or would like more information about melanoma, then this guide is for you.

## Note to reader:

The information in this book is of a general nature and should not replace the advice of your health professionals. You may wish to discuss issues raised in this book with them. All care has been taken to ensure the information presented here is accurate at the time of publishing. Always consult your doctor before beginning any health treatment.

# Contents

<b>About melanoma</b> .....	<b>3</b>	<b>Follow-up care</b> .....	<b>41</b>
What is melanoma? .....	4	What is follow-up care? .....	42
What is Stage III melanoma? .....	8	Self examination .....	45
<b>Diagnosing and staging melanoma</b> .....	<b>9</b>	Questions to ask your healthcare team .....	49
Initial diagnosis .....	10	<b>Keeping well</b> .....	<b>51</b>
Checking for spread .....	11	Understanding your risk factors for melanoma .....	52
Pathology results .....	13	Sun protection .....	53
Staging melanoma .....	17	A healthy lifestyle .....	55
Prognosis .....	21	Coping and emotional wellbeing .....	57
Questions to ask your healthcare team .....	22	Seeking support .....	58
<b>Treating Stage III melanoma</b> .....	<b>23</b>	Information and support for loved ones .....	60
An important note on treatment .....	25	<b>Your melanoma organiser</b> .....	<b>61</b>
The approach to treating Stage III melanoma .....	26	Personal details .....	63
Surgery .....	27	Medical information .....	65
Radiation therapy .....	32	My diagnosis summary .....	67
Systemic therapies .....	34	My treatment plan .....	68
Unresectable melanoma .....	38	My follow-up plan .....	74
Clinical trials .....	39	My healthcare team .....	78
Questions to ask your healthcare team .....	40	My appointments .....	81
		Medication chart .....	84
		Medical expenses .....	86
		My notes and questions .....	88
		<b>Glossary</b> .....	<b>92</b>

# Foreword

Melanoma is a familiar word to most Australians. But it's only when melanoma directly impacts our lives that we begin to understand the potential seriousness of this type of skin cancer.

As the world's leading melanoma research and treatment centre, Melanoma Institute Australia is committed to finding new ways to prevent, treat and promote awareness of this disease.

When receiving a diagnosis of melanoma, finding the right information that you can trust is extremely important. That's why Melanoma Institute Australia has developed this guide and a comprehensive website, **[melanoma.org.au](http://melanoma.org.au)**, to make it easier for you to access reliable and expert information.

We believe that, with this support, you will be better equipped to focus on your health and wellbeing, confident in the information you are receiving.

Regards,  
Professor Georgina Long and Professor Richard Scolyer  
Conjoint Medical Directors  
Melanoma Institute Australia





# About melanoma

# What is melanoma?

Melanoma is a form of cancer that develops in the body's pigment cells, known as melanocytes. Melanoma occurs when abnormal melanocytes grow in an uncontrolled way and evade the immune system.

While melanoma usually begins in the skin (cutaneous melanoma), less commonly it can start in the eye (ocular melanoma) or the moist tissue that lines certain parts of the inside of your body (mucosal melanoma). It can occur anywhere you have melanocytes, even if they are not exposed to sunlight.

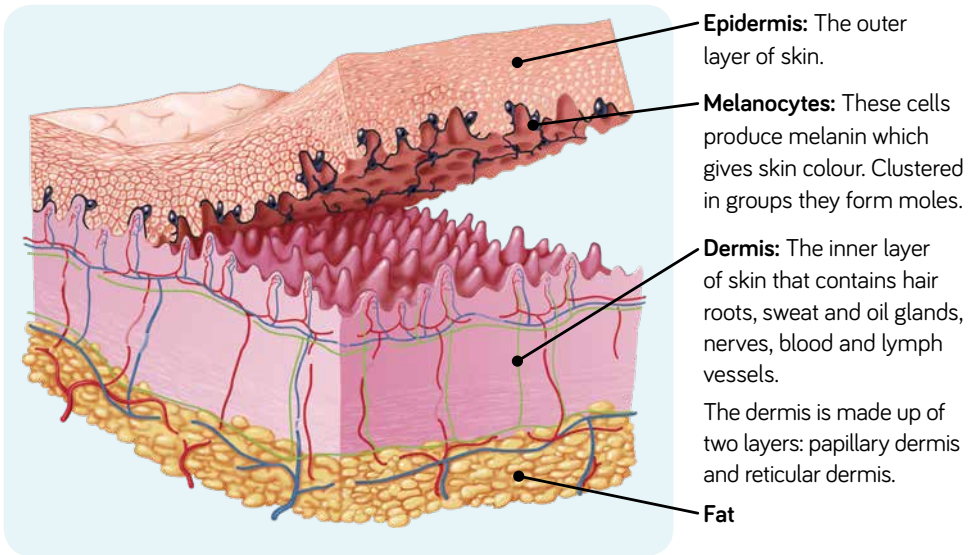
A primary melanoma is the site of origin of a melanoma.



Australia has **one of the highest rates** of melanoma in the world.



# The skin



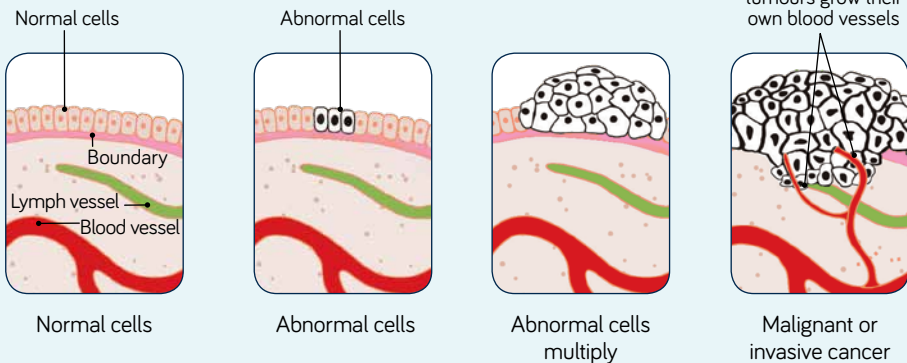
On average, **38 Australians** will be diagnosed with melanoma every day.

# How cancer grows and spreads

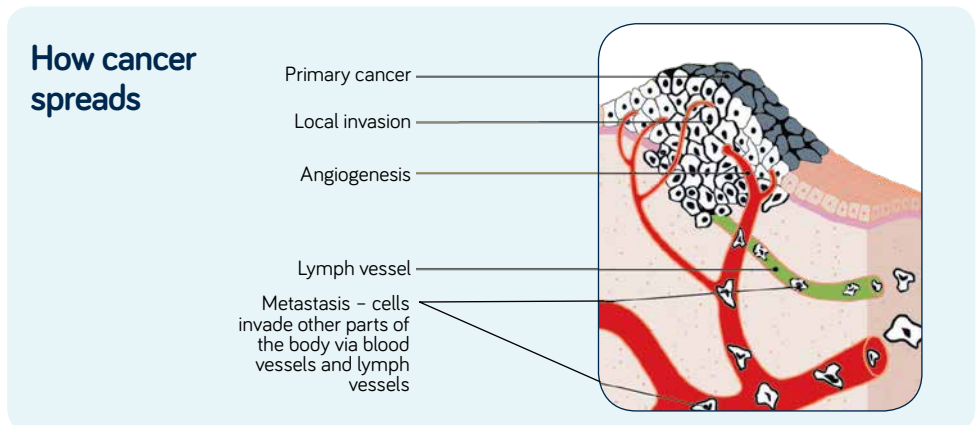
The body is made up of billions of cells that form tissues and organs. Healthy cells grow and duplicate in a controlled way, replacing old and damaged cells as the body requires.

Cancer occurs when abnormal cells grow and divide in an uncontrolled manner, forming a tumour.

## How cancer starts



As a tumour gets bigger, cancer cells may spread to nearby tissue and structures. Cancer cells can also spread to other areas of the body through the blood or lymphatic systems. This process is called metastasis.



Adapted from Cancer Council Victoria. Illustration by Paul Sloss.

# What is Stage III melanoma?

The stage of a cancer is used to describe the characteristics of the primary tumour and whether it has spread (metastasised) to other parts of the body. Melanoma can be described as Stage 0, I, II, III or IV.

Stage III melanoma is melanoma that has spread from the site where it began to nearby lymph nodes or to surrounding tissue (in-transit disease).

You can read more about each stage of melanoma on pages 17–18.

Treatment for melanoma depends on a number of factors, including stage. You can read more about treatment for Stage III melanoma on pages 23–40.



# Diagnosing and staging melanoma

# Initial diagnosis

Everyone's experience of melanoma is unique. In this section, we explore some of the procedures involved in diagnosing and staging melanoma. You may have had one or more of these procedures.

If you have any questions about your diagnosis or staging, speak with a member of your healthcare team.

## Biopsy

Most melanoma diagnoses start with a physical examination of a suspicious looking spot or lesion on the skin. Your doctor will have assessed this spot or lesion and decided to perform a biopsy to investigate it further.

A biopsy is the removal of a tissue sample from the suspicious area so that it can be sent to a pathologist for examination.

Common biopsy procedures include:

**Excision biopsy:** a scalpel is used to remove the entire suspicious area with a 2mm margin, down to the subcutaneous layer.

**Punch biopsy:** an instrument known as a 'punch' is used to remove a circular sample of the suspicious area.

**Incision biopsy:** a scalpel is used to remove a portion of the suspicious area for examination.

**Shave biopsy:** a razor is used to shave a superficial sample from the suspicious area.

**Fine needle biopsy:** a needle, similar to that used for blood collection, is inserted into the suspicious area to collect a sample of cells.

Regardless of the type of biopsy that you had, a pathologist would have examined your tissue sample under a microscope to determine if it contained melanoma cells. The results of this biopsy would have been provided to your doctor in a pathology report.

You can read more about your pathology report on page 13.

# Checking for spread

The body's lymphatic system is a network of nodes and vessels running throughout your body that help to filter waste. The lymphatic system plays a key role in your body's immune response to infection.

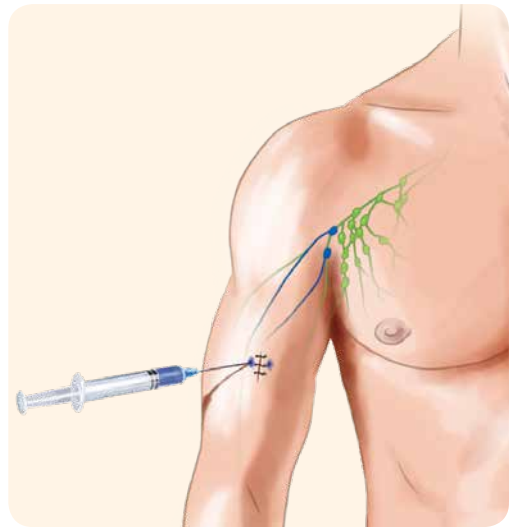
Sometimes melanoma cells can travel through lymphatic vessels to other areas of the body. Lymph nodes filter the fluid running through your lymphatic vessels, trapping large molecules like bacteria, viruses and cancer cells, so that the immune system can attempt to destroy them.

Your doctor may check surrounding tissue and the lymph nodes near a melanoma to see if any cancer cells have spread.

## Sentinel node biopsy

If the results of your initial biopsy indicate that your primary melanoma has a moderate-to-high risk of spreading, your doctor may suggest a procedure called a sentinel node biopsy.

The sentinel node is the first lymph node or nodes that filter lymphatic fluid from the area of skin that has melanoma. If the cancer has spread, the sentinel node is the most likely node to have cancer in it.



**Mapping sentinel lymph nodes:** an injection of dye around the primary melanoma site shows the first lymph node(s) that this area of skin will drain to.

You can read more  
about Sentinel  
Node Biopsy at  
[melanoma.org.au](http://melanoma.org.au)



To find the sentinel node, a radioactive dye is injected around the area of skin that has melanoma. The dye maps the lymphatic vessels in the area and highlights the location of the sentinel node or nodes. The most common areas that melanoma can drain to are the neck, axilla (armpit) and groin lymph nodes.

The sentinel node or nodes can then be surgically removed and sent for testing. If the nodes test positive for melanoma you will see a surgeon to discuss further treatment which may include a complete lymph node dissection, where all lymph nodes in the affected area are removed, or drug treatment. You can read more about lymph node dissection on page 28.

### **Fine needle biopsy**

If you present with an enlarged lymph node which may be felt as a lump under the skin, your doctor will usually perform a fine needle biopsy or core biopsy to examine cells inside the lump for the presence of melanoma.

A fine needle biopsy involves inserting a thin needle into the suspicious lump to collect a sample of cells.

If the results of this biopsy test positive for melanoma you will see a surgeon to discuss a complete lymph node dissection, where all lymph nodes in the affected area are removed.

### **Satellite and in-transit disease**

Sometimes melanoma cells may have spread from the primary site but not yet have reached a lymph node. The cells may present on the skin's surface (called satellite disease) or as a lump felt under the skin (called in-transit disease).

If you present with in-transit disease, your doctor will usually perform a fine needle biopsy or excision biopsy on the lump to confirm it is melanoma. If the results from this biopsy confirms melanoma, you will see a surgeon to discuss further treatment.



# Pathology results

Following your biopsy, you will receive a pathology report that will contain a detailed description of your tissue sample. It may look similar to the example shown on the following page. Your doctor will explain what your results mean and how this will determine further treatment.

The terms typically used in pathology reports are explained on the next few pages and will help you to understand what your results mean. If you have further questions, talk to your doctor.

## How long do pathology reports take?

A complete pathology report can take up to two weeks to prepare. This report contains information that will guide your treatment. If at any time you would like a copy of your pathology report, you can request one from your doctor.

## The parts of a pathology report

### Macroscopic description

This is a description of what the pathologist sees when looking at your sample with the naked eye.

### Microscopic description

This is a description of what the pathologist observes from looking at your tissue sample under the microscope. It provides more technical and diagnostic information.

The specimen type refers to the biopsy method used to obtain a sample of your tissue. The site is the area on your body where the biopsy came from. This part of the report may describe the size of the sample and the size and appearance of any lesion within it.

## Sample pathology report

**Patient name:** SMITHSON, Mary

**DOB/Sex:** 1/01/1951, F

**Requested by:** Dr Jackson, Sally

**Requested on:** 01/05/2018

**Specimen received:** 02/05/2018

## PATHOLOGY REPORT

### CLINICAL DETAILS

Changing lesion, right back.

### MACROSCOPIC

Ellipse of skin measuring 30x10mm to a depth of 6mm with a lesion 3x7mm in diameter.

### MICROSCOPIC REPORT

Specimen type: Excision

Site: Right back

Diagnosis: Melanoma

Classification/Main pattern: Nodular

Thickness: Breslow 2.6mm

Clark level: IV

Ulceration: Present

Dermal mitoses: 5 per mm<sup>2</sup>

### SUMMARY

Skin right back, excision, NODULAR MELANOMA

## Diagnosis

Diagnosis states the type of cells found within the tissue sample. This will be confirmed again in the summary of the report.

## Type/classification

There are several different classifications of cutaneous melanoma. Each classification has different characteristics with a different pattern of behaviour. Your pathology report will outline how your melanoma is classified.

### Superficial spreading melanoma



This is the most common type of melanoma making up more than 50% of all melanomas diagnosed. This melanoma usually appears as a dark spot with irregular borders that spreads across the skin.

### Nodular melanoma



Nodular is one of the most rapidly growing types of melanoma. It appears as a raised lump or 'nodule' and can be brown, black, pink or red in colouring, or have no colour at all. About 15% of all melanomas are nodular.

### Lentigo maligna melanoma



Lentigo maligna melanomas begin as large freckles. They are commonly found in older people, often in areas that have received a lot of sun exposure such as the face, head, neck and upper body. This type of melanoma makes up 10% of all melanomas.

### Acral lentiginous melanoma



Acral is a rare type of melanoma that tends to grow on the palms of hands, soles of the feet or under the nails (subungual). It accounts for about 3% of all melanomas.

Other, less common types of cutaneous melanoma include desmoplastic and naevoid melanoma. Non-cutaneous melanomas include mucosal melanoma, found in tissues lining the respiratory, digestive, and reproductive tracts and ocular (including uveal) melanoma which develops in the eye.

### Breslow thickness

Breslow thickness describes the depth of your melanoma in millimetres. This is very useful information to stage your melanoma, indicate the risk of it spreading and guide appropriate treatment.

Thickness	Description
Less than 1mm	Thin melanoma
1–4mm	Intermediate thickness melanoma
Greater than 4mm	Thick melanoma

### Clark level

Your pathology report may also show a Clark level. This is a scale from I–V (Roman numerals) to describe which layer of the skin the melanoma cells have invaded (i.e. from the superficial epidermis through to the deeper subcutaneous tissue). A Clark level of I is the shallowest and V is the deepest level of invasion. Clark levels are not to be confused with stages of melanoma.

A Clark level measurement differs to a Breslow thickness measurement as it depends on the pathologist's judgement of skin layers. Breslow thickness gives a very accurate measurement for staging a melanoma. However, a Clark level is also helpful as it can tell us if a melanoma is more advanced than the Breslow thickness indicates.

### Ulceration

Ulceration is the absence of the top layer of skin over the melanoma. The presence or absence of ulceration is used to help determine the stage of melanoma. The depth of an ulcerated lesion cannot be accurately reported in the Breslow thickness. The presence of ulceration can be associated with a deeper lesion, a faster growing melanoma and, therefore, a worse prognosis.

### Mitotic rate

Mitotic rate measures the number of dividing melanoma cells (mitosis) per mm<sup>2</sup> and can indicate how quickly the melanoma cells are growing. Higher mitotic rates (e.g. greater than 5 per mm<sup>2</sup>) indicate faster growing melanoma and are associated with a worse prognosis.

### Surgical margin

The report may describe the presence or absence of melanoma cells at the edges or deepest part of the sample (surgical margins). If these margins are positive (melanoma cells are present) more surgery may be needed.

### Lymph node status

If you have had a fine needle biopsy, the pathology report will state whether there was melanoma in the biopsy sample. If you have had a sentinel node biopsy, or you have had lymph nodes removed during surgery, the pathology report you receive after these procedures will record information about the number of nodes retrieved, the number of nodes containing melanoma and whether the melanoma has breached the node (called extra-nodal spread).

# Staging melanoma

Staging a melanoma provides a description of its size and whether it has spread to other parts of the body.

While you may see many numbers on your pathology report, generally your stage will not be listed. Your doctor will discuss the stage of your melanoma with you.

Characteristics described in your pathology report help to determine the stage of your melanoma and guide your treatment approach. In most cases, the stage of a cancer is based on three factors:

- The location and size of the original (primary) **tumour (T)**
- Whether or not the cancer has spread to nearby lymph **nodes (N)**
- Whether or not the cancer has spread to distant areas of the body, known as **metastasis (M)**

These combined factors are known as the TNM staging system. The TNM Staging System was developed by the American Joint Committee on Cancer (AJCC) and the Union for International Cancer Control (UICC). It helps doctors to stage different types of cancer based on certain, standardised criteria.

Stage	What does this mean?	Likely course of action
Stage 0 (in-situ)	Melanoma is confined to the cells in the top layer (epidermis) of the skin. The melanoma has not invaded deeper layers (dermis) where there are lymphatic and blood vessels to spread to.	<ul style="list-style-type: none"> <li>– Surgical removal (wide local excision)</li> </ul>
Stage I	Melanoma can be up to 2mm in thickness without ulceration; or up to 1mm in thickness with ulceration.	<ul style="list-style-type: none"> <li>– Surgical removal (wide local excision)</li> <li>– Sentinel node biopsy may be considered to rule out spread of melanoma to lymph nodes</li> </ul>
Stage II	Melanoma can be over 2mm in thickness without ulceration; or 1mm to >4mm in thickness with ulceration and no lymph node spread.	<ul style="list-style-type: none"> <li>– Surgical removal (wide local excision)</li> <li>– Sentinel node biopsy may be considered to rule out spread of melanoma to lymph nodes</li> </ul>
<b>Stage III</b>	<b>Melanoma has spread to local lymph nodes or nearby tissues (in-transit disease).</b>	<ul style="list-style-type: none"> <li>– <b>Surgical removal (wide local excision) for in-transit disease</b></li> <li>– <b>Lymph node dissection (removal of all lymph nodes in the affected region)</b></li> <li>– <b>Consideration of additional treatments before or after surgery, such as radiation therapy or drug (systemic) therapies</b></li> </ul>
Stage IV	Melanoma has spread (metastasised) to distant lymph nodes or to distant parts of the body (e.g. lung, liver, brain, bone).	<ul style="list-style-type: none"> <li>– Surgery or systemic therapy may be used</li> <li>– Radiation therapy may also be considered</li> </ul>

# A closer look at Stage III melanoma

Stage III melanoma means that cancer cells have spread into the skin lymphatic vessels and/or lymph nodes close to the original (primary) melanoma. The melanoma has not spread to other areas of the body.

Stage III is further classified into four subgroups, based on the TNM staging factors. In Stage IIIA, melanoma present in the lymph nodes is microscopic (diagnosed with a sentinel node biopsy). For Stage IIIB, IIIC and IIID, the lymph node is enlarged and palpable and a lump is present. The characteristics of each subgroup have been summarised in the table below.

Stage	Characteristics
IIIA	<ul style="list-style-type: none"> <li>- The cancer is no more than 2mm thick. It may or may not be ulcerated.</li> </ul> <p><b>AND</b></p> <ul style="list-style-type: none"> <li>- The melanoma has spread to up to 3 nearby lymph nodes, but it is so small that melanoma cells can only be seen under a microscope.</li> </ul>
IIIB	<ul style="list-style-type: none"> <li>- There may be no sign of the primary melanoma. However, melanoma cells have spread to 1 lymph node OR to very small areas of nearby skin or lymphatic vessels.</li> </ul> <p><b>OR</b></p> <ul style="list-style-type: none"> <li>- The melanoma is up to 4mm thick. It may or may not be ulcerated. Melanoma cells have spread to up to 3 lymph nodes OR to very small areas of nearby skin or lymphatic vessels.</li> </ul>

Stage	Characteristics
IIIC	<ul style="list-style-type: none"> <li>- There may be no sign of the primary melanoma. However, melanoma cells have spread to 1 or more lymph nodes OR to lymph nodes that are clumped together OR to very small areas of nearby skin or lymphatic vessels.</li> </ul>
	<p><b>OR</b></p> <ul style="list-style-type: none"> <li>- The melanoma is up to 4mm thick. It may or may not be ulcerated. Melanoma cells have spread to 1 or more lymph nodes OR to lymph nodes that are clumped together OR to very small areas of nearby skin or lymphatic vessels.</li> </ul>
	<p><b>OR</b></p> <ul style="list-style-type: none"> <li>- The melanoma is between 2.1 and 4mm thick, or thicker than 4mm. It may or may not be ulcerated. Melanoma cells have spread to 1 or more lymph nodes OR to lymph nodes that are clumped together OR to very small areas of nearby skin or lymphatic vessels.</li> </ul>
	<p><b>OR</b></p> <ul style="list-style-type: none"> <li>- The melanoma is thicker than 4mm and is ulcerated. Melanoma cells have spread to more than 3 lymph nodes OR to very small areas of nearby skin or lymphatic vessels.</li> </ul>
IIID	<ul style="list-style-type: none"> <li>- The melanoma is thicker than 4mm and is ulcerated. Melanoma cells have spread to 4 or more lymph nodes OR to lymph nodes that are clumped together OR to very small areas of nearby skin or lymphatic vessels.</li> </ul>

This information is based on the 8th edition of the American Joint Committee on Cancer Staging Manual, implemented from January 2018. Speak with your doctor to confirm if your staging has been based on the 7th or 8th edition of the Staging Manual.



# Prognosis

A person's prognosis can depend on the type and stage of melanoma, age, genetics, general health at the time of diagnosis and how well you respond to treatment.

Some people find it helpful or reassuring to talk about prognosis. Others find this confronting and some people may not want to know about it at all.

You may like to talk to a professional, such as a counsellor or psychologist, or join a support group to discuss your response to finding out about your prognosis. You can read more about accessing this support on page 58.

If you would like to know about prognosis for your specific circumstance, speak with your doctor.

## Support for you



### Questions you may want to ask your healthcare team

- What type of melanoma do I have?
- What is the stage of my melanoma? And what does this mean?
- How does the stage of my melanoma affect my treatment choices and long-term outcomes?
- How do I get a copy of my pathology report?
- Is it possible to cure or control my melanoma?



# Treating Stage III melanoma



# An important note on treatment

Current melanoma research is fast-paced and ever-changing. Every day, research into new treatments for melanoma is being undertaken.

Exciting research outcomes may mean that new treatments will become available to patients over time. Access to new treatments will depend on the approval of government bodies such as the Therapeutic Goods Administration (TGA), which licenses drugs for use in Australia, and the Pharmaceutical Benefits Scheme (PBS), which subsidises the cost of certain drugs for patients.

The content contained in this section of the guide provides an overview of treatment options available for Stage III melanoma at the time of publishing.

We acknowledge that in this ever-changing environment, treatment options may change. As such, the content has been kept general in nature.

If you would like more specific information about your treatment options, speak with a member of your healthcare team who will know the best course of treatment for you based on your individual health circumstances.

# The approach to treating Stage III melanoma

If you have been diagnosed with Stage III melanoma you may have a combination of different treatments, including:

- Surgery
- Radiation therapy
- Systemic therapy (treatment with drugs).

Surgery and radiation therapy are local treatments. This means they only affect the specific area of the body treated.

Systemic therapy uses the bloodstream to deliver drugs to the whole body.

You may have one or more of these treatments for your melanoma.

Some of the treatments given can cause mild to severe side effects or complications. It is important that you contact your local doctor, clinic nurse or specialist doctor if you have any concerns. Most side effects are temporary and can be managed by your doctor.

**In an emergency or after hours, always go to your closest hospital for care.**

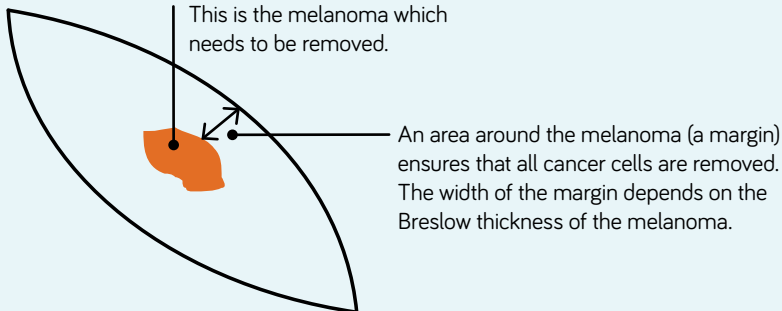
# Surgery

## Wide local excision

*(If the primary melanoma is still present)*

A primary melanoma always requires surgical removal. This surgery is called a wide local excision. It involves removal of more tissue at the site of the initial biopsy, including a margin of healthy skin around and deeper to the melanoma to increase the likelihood that all cancer cells are removed. In-transit disease can also be removed with wide local excision.

If the wound is small it can usually be closed with stitches, staples or clips. Larger wounds may require a skin flap or skin graft at the time of surgery to close the wound created by removing the melanoma. The need for a skin flap or a skin graft will depend on the location and size of the tissue that is being removed.



## Lymph node dissection

Melanoma that has spread to nearby lymph nodes may require the removal of all the lymph nodes in the affected area. This is called a lymph node dissection and may be performed at the same time as the wide local excision or as a subsequent surgery.

Your surgeon will talk to you about the benefits of undergoing a lymph node dissection.

There are three main types of lymph node dissection:

- **Axillary dissection** removes all the lymph nodes and possible tumour-containing tissue from the armpit region.
- **Groin dissection** removes all the lymph nodes from the groin (inguinal lymph node dissection) or all the lymph nodes from the groin and pelvis (ilio-inguinal lymph node dissection).
- **Neck dissection** (also known as cervical lymph node dissection) removes affected lymph nodes in the neck region. The extent of node clearance is determined by the location of the original melanoma and how far it has spread.

Lymph node dissection is conducted under a general anaesthetic and will require you to stay in hospital up to seven days after surgery. Depending on the type of dissection performed, you may need additional recovery time before returning to normal activities once you are home from hospital.

Visit [melanoma.org.au](https://www.melanoma.org.au) for more information about lymph node dissection.





## Side effects of surgery

After your surgery, you may experience some side effects or complications that can affect your recovery. It is difficult to know exactly what side effects you will experience as everyone reacts differently to surgical procedures.

The most common side effects and complications include:

- **Pain.** This will begin to subside once you start to heal. Pain can be managed with different types of pain medications. You can help to control your pain by taking your pain medications regularly, as prescribed by your doctor.
- **Infection.** Signs that your wound may be infected include an increase in pain and redness around the wound, pus or odour coming from the wound and fever. Most infections are minor and respond well to antibiotics.
- **Bleeding or bruising.** You may notice some minor bleeding from or bruising around the wound. Bleeding should settle within a few days, and bruising will fade with time.
- **Nerve damage.** During surgery to remove lymph nodes, it can be difficult to avoid damaging nearby nerves. This may cause you to have temporary or permanent nerve damage in the affected area.
- **Seroma.** A seroma is a collection of fluid in and around your wound; this is different to an infection. The fluid gets caught in a pocket underneath the skin. As this may increase the risk of developing an infection, it is important that it is reviewed by your doctor or specialist nurse and either observed or drained. It is usually drained using a needle and syringe or by inserting a drain.

Side effects can occur immediately or in the weeks after your surgery. If you are concerned about any side effects that you have, speak with a member of your healthcare team. If you experience severe symptoms after your surgery, such as heavy bleeding, shortness of breath or severe pain, seek urgent medical attention.

## Looking after yourself after surgery

### Personal care

After your surgery you can usually shower as normal, but avoid spraying water or putting soap directly on the surgical site or drain area. Gently pat yourself dry in the operated area with a clean towel.

Avoid swimming or soaking in a bath until your stitches/staples and drain have been removed. Avoid using cosmetic creams, perfume, deodorant and other topical products on the area until the wound has completely healed.

### Drain care

After your lymph node surgery, you will have one or two drains in place to help your body remove any excess fluid or blood. If you are going home with a drain, a community nurse will visit to help care for your surgical site and drain.

Your drain may need to be milked every 4 hours during the day. Your nurse will show you how to do this. The drain site can be left exposed or covered with a dressing to be changed as needed. It is important to monitor the output from the drain. Every 24 hours, empty, measure and record your drain volumes. If you notice a sudden

increase in swelling or redness in the affected limb or around the drain site, if the output in the drain suddenly increases, the fluid changes colour or the drain starts to leak around the insertion site, please contact your doctor or specialist nurse.

### Why do I need a drain?

The main function of your lymph nodes is to receive and filter lymph fluid. After surgery, you will not have any lymph nodes in this particular area so the fluid has to be re-directed by your body to other areas that contain lymph nodes. A drain will remove fluid from the surgical cavity and allow the site to close down and heal.

Once your body has adjusted to the change of not having any lymph nodes in a particular area the fluid drained will gradually reduce. The drain can then be removed.

### Wound healing

You may have sutures or metal clips holding your wound together. They are normally removed 10–14 days after your surgery. It is important you keep the area clean and dry after your surgery. Before you leave the hospital, the nursing staff will let you know how to care for your surgical site.

If your surgical site becomes red, swollen, excessively sore or oozes a lot this could be a sign of infection. If you have any concerns please contact your doctor or specialist nurse for advice.

### Moving around

You may find your ability to move around is restricted because of the location or the extent of your surgery.

This should eventually improve once the wound has healed.

At home, start with gentle movement. Avoid exercise that may stretch the surgical site for at least 2–3 weeks or until the drain has been removed. If you are finding it difficult to get your full range of movement back, you may benefit from seeing a physiotherapist who can help you.

### Lymphoedema

Lymphoedema is swelling in the limb or tissues where lymph nodes were removed due to retained fluid. The swelling can interfere with function or cause discomfort.

You can expect some swelling around the wound and possibly in the affected limb. This is not lymphoedema. It is part of the normal healing process and usually subsides a few weeks after surgery.

Lymphoedema mostly happens within 12 months of melanoma surgery but may occur years later. It can be triggered by trauma to the limb such as infections or skin damage.

Lymphoedema is treated by lymphoedema specialists and can be managed well if caught early.

Radiotherapy can also increase the risk of lymphoedema. If you are going to have radiotherapy, you can ask your doctor for a referral to a lymphoedema specialist before you start your radiotherapy treatment.

Your doctor can arrange Medicare cover for you to receive some financial assistance towards this appointment.

Melanoma Institute Australia has developed a variety of patient information brochures covering topics such as exercises following lymph node dissection and lymphoedema.

Visit [melanoma.org.au](http://melanoma.org.au) to find out more.



# Radiation therapy

Radiation therapy uses x-rays to target and kill cancer cells by damaging their DNA.

Normal cells can repair damage to their DNA, but cancer cells are less able to do this and therefore die when affected by radiation therapy. The dead cancer cells are then broken down and eliminated by the body's natural processes.

Since radiation therapy damages normal cells as well as cancer cells, treatment must be carefully planned to allow the normal cells to repair themselves and minimise side effects. A radiation oncologist is a doctor who specialises in radiation therapy and will plan and monitor your treatment.

The total dose of radiation and the number of treatments you need will depend on the size and location of your melanoma, your general health and other medical treatments you're receiving.

The radiation used for cancer treatment can come from a machine outside your body or it might come from radioactive material placed in your body near the cancer cells.

Radiation therapy may be given on its own, after surgery or in combination with another drug therapy.

## Side effects of radiation therapy

Radiation therapy is not painful, but can cause some side effects. Your radiation oncologist and nurse will see you regularly to monitor your progress and manage any side effects.

Side effects from radiation therapy normally occur toward the end of your treatment or a few weeks after you have completed the treatment and may include:

- temporary or permanent loss of hair in the area being treated
- skin irritation, including dry, itchy or blistering skin
- temporary change in skin colour in the treated area
- tiredness.

Visit [melanoma.org.au](https://www.melanoma.org.au) for more information about radiation therapy.



# Systemic therapy

Systemic therapy uses drugs that travel through your bloodstream to target and affect cancer cells throughout the body.

A medical oncologist is a doctor who specialises in systemic therapy and will plan and monitor you during your treatment.

In Stage III melanoma, systemic therapies are sometimes recommended to reduce the chance of the melanoma recurring (coming back). Currently, there are two main types of systemic therapy used to treat melanoma: targeted therapy and immunotherapy.

## Targeted therapy

Targeted therapies are drugs that block the growth of cancer by interfering with specific gene mutations in melanoma cells that allow melanoma to grow and spread. This is different to non-specific treatments, like chemotherapy, that simply aim to kill rapidly dividing cells.

Researchers have identified some of the key genetic mutations that drive the growth of melanoma in patients, including:

- BRAF (“BEE-raff”). Almost 40% of Australian melanoma patients have a BRAF mutation.
- NRAS (“EN-rass”). Approximately 25% of Australian melanoma patients have a NRAS mutation.
- cKIT (“SEE-Kit”). cKIT mutations are rare (less than 4% of patients).

Another type of gene, called MEK, works together with the BRAF gene to drive melanoma growth. This means, drugs that block the MEK gene can help to treat melanomas with BRAF mutations.

Currently, there are two targeted therapy regimens that are approved for use in patients with a BRAF-mutation. These regimens combine a drug that targets the

### eviQ

You can read more about different drug treatments in the eviQ patient information sheets, available at: [eviQ.org.au/patients-and-carers](http://eviQ.org.au/patients-and-carers)



BRAF gene mutation (BRAF inhibitor) with a drug that blocks the MEK gene (MEK inhibitor). The combination of a BRAF inhibitor and a MEK inhibitor has been found to be more effective for shrinking melanoma tumours than using either type of drug on its own.

The combinations are:

- a BRAF inhibitor called dabrafenib and a MEK inhibitor called trametinib.
- a BRAF inhibitor called vemurafenib and a MEK inhibitor called cobimetinib.

There are currently no therapies available specifically to treat NRAS-mutant or cKIT-mutant melanomas, though some are being tested in clinical trials.

More mutations are continuing to be discovered and new treatments specific to these mutations are in development and being tested in clinical trials.

Speak with your healthcare team to find out about any new advances in targeted therapy that may be relevant to you.

### Getting tested for melanoma mutations

Your doctor may talk to you about a test to look for genetic mutations in the DNA of your melanoma. The test can be performed on melanoma tissue that was taken during a previous biopsy or surgery.

If your melanoma has a specific mutation, it may make you a suitable candidate for a specific targeted therapy.

Not all melanomas have mutations that can currently be targeted with drugs. It is not a good or bad thing if your melanoma does not have a mutation – it just means that the treatment offered to you will be different to someone who does have a targetable mutation.

Visit [melanoma.org.au](http://melanoma.org.au) for more information about targeted therapies.



### Side effects of targeted therapy

The most common side effects seen with targeted therapy include fever, diarrhoea and liver problems, such as hepatitis or elevated liver enzymes.

Other side effects may include:

- skin problems (rash, dry skin, sensitivity to light)
- problems with healing or blood clotting
- high blood pressure.

Different types of targeted therapy will cause different side effects. You should speak to your healthcare team about what to expect from your specific drug before commencing treatment.

### Immunotherapy

Immunotherapy (also known as immune therapy) works by activating the body's own immune system to seek out and fight melanoma cells. Immunotherapy can be used to treat melanoma of the skin, regardless of your genetic mutation test result.

There are two types of immunotherapy that can be used to treat Stage III melanoma:

- Checkpoint inhibitors block proteins on the surface of melanoma cells that usually stop the body's immune system from killing the cancer cells. When these proteins are blocked, your immune system's ability to kill the cancer cells is increased. Ipilimumab, nivolumab and pembrolizumab are checkpoint inhibitors that are approved for the treatment of unresectable Stage III and Stage IV melanoma.
- Interferon is similar to a protein that your body normally produces to fight infection. It works by affecting the division of cancer cells and slowing cancer growth. It is now used less often in the treatment of melanoma, as other therapies have been proven to be more effective and with fewer side effects.

### Understanding Immunotherapy

Resource available from Cancer Council:  
[cancercouncil.com.au](http://cancercouncil.com.au)





Other immunotherapies are being tested in clinical trials. Speak with your healthcare team to find out about any new advances in immunotherapy that may be relevant to you.

### Side effects of immunotherapy

Immunotherapy can sometimes cause the immune system to attack healthy cells in the body. This can result in side effects.

The most common side effects of immunotherapy include:

- Diarrhoea
- Mouth sores
- Skin problems (redness, dry skin, blistering)
- Flu-like symptoms (feeling tired, fever, weakness)

Different types of immunotherapy cause different side effects. You should speak to your healthcare team about what to expect from your specific drug before commencing treatment.

# Unresectable melanoma

Unresectable melanoma is melanoma that cannot be removed with surgery.

Treatment recommendations for people with unresectable Stage III melanoma depend on a number of factors, including:

- age and overall health
- where and how much the melanoma has spread
- the rate at which the melanoma is spreading
- any specific genetic mutations in the melanoma tumour
- the patient's preferences.

Radiation and/or systemic therapy may be suitable treatment options for unresectable melanoma.

# Clinical trials

Having been diagnosed with Stage III melanoma, you may be offered participation in a clinical trial or a research study.

Clinical trials are a crucial part of the research undertaken at research institutes and hospitals around the country. Trials are conducted to help find better ways to prevent, screen, diagnose or treat melanoma, and to potentially improve the quality of life of those who have this disease.

Each clinical trial has a set of criteria for who is eligible to join the trial. These criteria may include factors such as your type of cancer, the stage and extent of the cancer, your age group and your overall wellbeing.

If you are interested in participating in a clinical trial, your healthcare team may find a trial that is suitable for you. Your healthcare team can use the Melanoma Institute Australia ClinTrial Refer Melanoma App to find the best possible clinical trial options available.

You can also enquire about a suitable clinical trial by asking your healthcare team or visiting the Australian Cancer Trials website ([australiancancertrials.gov.au](http://australiancancertrials.gov.au)).

## Understanding Clinical Trials and Research

Resource available from Cancer Council:  
[cancercouncil.com.au](http://cancercouncil.com.au)



# Support for you



## Questions you may like to ask your healthcare team

- What are my treatment choices?
- What is the goal of my treatment?
- Will I be ok if I just have surgery and no other treatments?
- What side effects should I expect from treatment?
- How can I reduce my risk of side effects?
- Can I make any lifestyle changes to help me manage my treatment and side effects?
- Will I be able to work during treatment?
- Should I get a second opinion? How do I do that?
- Are there any clinical trials available to me?



# Follow-up care

# What is follow-up care?

Attentive follow-up care is important after treatment for any melanoma to monitor for recurrence and to check for other primary melanomas.

Attending follow-up appointments is a good way to monitor your health and to make sure that any concerns are dealt with quickly. Ask your doctor who is going to manage your follow-up care. Some people have check-ups with their GP or dermatologist, others may see their surgeon. In some cases, follow-up care is shared between two doctors.

## Follow-up schedule

How often your doctor will see you for follow-up appointments depends on several factors, including the stage of the melanoma, your treatment, your particular risk factors for recurrence and your general risk for developing other types of less worrying skin cancers, such as basal cell carcinomas (BCC) and squamous cell carcinomas (SCC).

In general, patients with a lower risk of recurrence may only need to attend annual follow-up appointments. Patients with a higher risk of recurrence may need to attend follow-up appointments every 3–6 months for the first 2–3 years after treatment.

Most recurrences of melanoma develop within the first five years after treatment, so your follow-up visits will be more frequent during this time. But late recurrence (even after 10 years) is also possible.

## What does follow-up care involve?

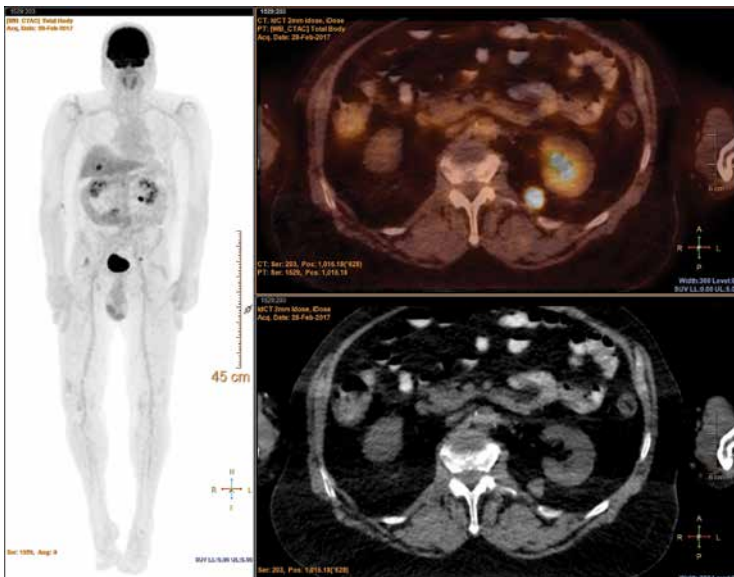
Follow-up involves a combination of physical examinations with your doctor and self examination. Your specific follow-up care plan will be guided by your melanoma history and any new or changing lesions that you or your doctor detect.

At each follow-up visit, your doctor will perform a thorough ‘top-to-toe’ physical examination – paying particular attention to the skin and lymph nodes – so that recurrence or a second primary melanoma may be detected early.

This physical examination may be aided by the use of total body photography to detect any changes in your skin.

Total body photography involves taking baseline photos of all of your skin. This provides a reference for comparison in future skin checks. These photographs can be used by you and/or your doctor.

In addition, your doctor may want laboratory tests (blood samples) and imaging studies (X-rays and scans). The types of tests done and how often they are done depend on the stage of the melanoma as well as the characteristics of your particular melanoma.



## Follow-up scans

Your doctor may order different types of imaging studies or scans as part of your treatment or follow-up care. Your doctor will decide how often and what type of scan you will have.

Imaging scans use different methods to create an image of your insides. You may need to prepare for these scans by fasting (no food or drink), and you may be given an intravenous injection before the scan to help produce an informative image of what is going on.

Please follow the instructions given to you by the imaging centre as each of these scans have different requirements.

- **Ultrasound** uses high frequency sound waves to look at internal structures. It is often used to look at smaller areas, like lymph nodes, or specific organs of the body.
- **X-rays** use a form of electromagnetic radiation to create two dimensional images of the body.

- **CT (computerised tomography)** uses x-rays to create an image of a cross section or very thin slice of the body. A CT shows the shape, size and location of lesions.
- **MRI (magnetic resonance imaging)** uses magnetic field and radio waves to produce images. An MRI is commonly used to look at joints, the brain and the spinal cord.
- **PET (positron emission tomography)** uses glucose tagged with radiotracers to observe how active cells are in the body. Sometimes PET and CT scans will be combined to give a more complete picture. (as shown in the picture on page 43).
- **Bone scans** use a specialised camera to take pictures of your skeleton.

If you are pregnant, diabetic, have a fear of needles, are claustrophobic or have any questions about how to prepare for your scans, contact the imaging centre where your scans will take place.



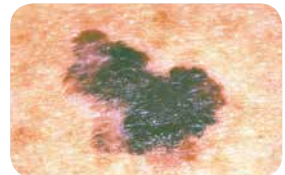
# Self examination

Being familiar with your skin will allow you to recognise changes early and act quickly. Your doctor will advise you on how often to check your skin.

## What to look for (ABCDE signs)

### Asymmetry

- A** Watch for spots with an irregular **shape**. If you run an imaginary line through the middle, does one half of the spot look similar to the other?



### Border

- B** Watch for spots that have an irregular or ill defined **border**.



### Colour

- C** Look for **changing colours** or spots with more than one colour, including black, brown, red, blue, white and uneven or blotchy colours.



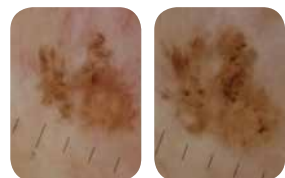
### Diameter

- D** Take note of any increase in **size**, rapidly growing spots or spots larger than 6mm.



### Evolution

- E** Look for **new marks**, freckles or moles. Look for spots that are **raised**. Be on the lookout for **changes** in existing spots, freckles or moles.



Some spots may not show any of the 'ABCDE' signs. For example, amelanotic

containing less brown pigment. They are often harder to detect because they aren't discoloured like other melanomas. They can be normal skin colour, or pink, red or purple.

As such, it's helpful to be aware of some other skin changes to look for during self examination. These include itchiness, tenderness or pain, and surface changes in moles such as those that become scaly, lumpy, or start to ooze or bleed. These changes need your immediate attention.

## Where to look

Make sure you check your entire body, including skin that is not normally exposed to the sun.

### Head, scalp, neck and ears

Use a hand-held mirror or ask someone to check areas you can't see easily.

### Torso: front, back and sides

Check front, back, then right and left sides with your arms raised.

### Arms, hands, fingers and nails

Look carefully at forearms and upper arms.

### Buttocks and legs

Check all sides from ankles to thighs.

### Feet, including soles and toes

Be sure to check your nailbeds.

Don't forget to check around your excision site including your lymph nodes for any new lumps. If you notice any of the signs described here, see your doctor as soon as possible.

If you have many moles, your doctor may recommend total body photography to assist in monitoring the skin.

Get to know the difference between melanomas and benign moles or benign lesions by familiarising yourself with these photos. In each instance, the photos shown on the left are a melanoma or a concern.

As these photos show, some differences between melanomas and benign moles can be very subtle. If you feel unsure about a mole, or any skin changes, always speak with your doctor.

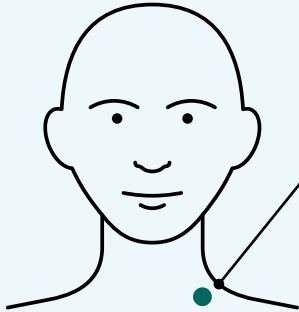


**Squamous Cell Carcinomas** and **Basal Cell Carcinomas** are other types of skin cancer. A history of melanoma can put you at increased risk of other skin cancers. If you have had any type of skin cancer it is a good idea to examine your own skin and schedule a professional skin examination with your doctor.

## Body maps

If you have moles or lesions you want to keep an eye on, simply draw them on the body maps on pages 76 and 77 along with the date and any comments.

### Example



1/01/2018 - new, 2mm, brown

4/01/2018 - checked by doctor

1/04/2018 - no change

1/07/2018 - changed: 3mm,  
red spots, needs checking by doctor

Apps for smart phones or tablets may be used to help you keep track of suspicious marks. They will NOT provide a diagnosis so ALWAYS follow up concerns with your health professional.

There are some apps that allow you to store images of your moles on your mobile phone and alert you when you need to take another photo. Some apps provide step-by-step instructions with images on how to examine your skin, others allow you to print or email information to your doctor.

## Support for you



### Questions you may like to ask your healthcare team

- What are the chances that my melanoma will come back after treatment?
- How often will I have follow-up exams and tests?
- How will I know if the melanoma comes back? What should I look for?
- Do I need to follow a special diet or exercise program?
- Are there any limits on what I can do?

# Notes

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**Keeping  
well**

# Understanding your risk factors for melanoma

Even when treatment is successful, having one melanoma puts you at increased risk of developing another primary melanoma.

Anyone can get melanoma but these factors increase your risk:

- A personal or family history of melanoma
- Mole count: if you have a lot of moles
- Unusual-looking, but non-cancerous moles (known as atypical moles)
- Fair skin
- Sunburn: If you have a history of sunburn and blistering, especially in childhood or adolescence
- UV exposure: You work outdoors, use sunbeds or actively seek a tan
- Age/gender: You are male and over 50 years

Melanoma can run in families. If you have been diagnosed with a melanoma, your close blood relatives (parents, siblings, and children) can be at increased risk, so regular skin checks are recommended for them.

Speak to your doctor if this is of concern to you. The Centre for Genetics Education has some information and a factsheet.

## Genetics

Resource available from [genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/Genetics-Fact-Sheets](http://genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/Genetics-Fact-Sheets) (go to factsheet 34)





# Sun protection

Sunscreen, protective clothing, sun shade and sun avoidance are ways to protect yourself which remain important even after you have been diagnosed with melanoma.



## Choosing sunscreen

The sunlight that reaches us on earth is made up of two types of harmful rays: long-wave ultraviolet A (UVA) and short-wave ultraviolet B (UVB) radiation. UVA radiation penetrates deep into your skin, causing premature aging and skin wrinkling. UVB radiation is responsible for causing sunburn on the superficial layers of your skin.

When selecting a sunscreen, choose a broad spectrum sunscreen with the highest possible SPF rating (currently SPF50+ in Australia).

‘Broad spectrum’ sunscreens provide protection against both UVA and UVB radiation. ‘SPF’ stands for sun protection factor. This is a measure of how effective the sunscreen is in protecting against sunburn. The higher the SPF rating, the more protection the sunscreen provides.

It’s important to remember that your protection from sunscreen will be affected by UV levels (higher levels mean faster burn time), your skin type (fair skin burns faster than olive or dark skin) and how well you have applied your sunscreen to begin with.

## Applying sunscreen

Most people do not apply enough sunscreen to achieve the SPF rating on the bottle. Apply your product generously, a teaspoon for each arm, each leg and on the front and back of your body and a teaspoon for your face, neck and ears (that’s 7 teaspoons or a shot glass full of sunscreen in total).

Reapplying your sunscreen every two hours is important as it often gets wiped or washed away.

Spread your product lightly and evenly on your skin and allow it to absorb. Do not rub it in completely as you may end up just rubbing it off.

### If my beauty products have SPF in them, do I still need sunscreen?

You need to consider whether the SPF in your products is high enough to provide the protection you need and whether you have applied enough to give you the correct coverage. Remember, you need a teaspoon of product to cover your face, neck and ears.

When you do reapply you will likely cover parts of your skin that were missed the first time around.

### Wearing protective clothing

Covering up with clothing is one of the best ways to protect your skin from the sun. Try to cover as much skin as possible with long pants and long-sleeved collared shirts.

Don't forget to protect your eyes as well by choosing sun protective eyewear that offer good sun glare and UV protection.

### A note on Vitamin D

Vitamin D is important for bone health and regulating the immune system.

Most people will get the vitamin D they need from sun exposure as they go about everyday outdoor activities. For most people, a few minutes outside everyday during summer months (either side of the peak UV period of 10am–2pm or 11am–3pm daylight saving time) is enough to maintain vitamin D levels.

You can also get small amounts of vitamin D from some food sources such as milk, eggs and fatty fish.

Normal use of sunscreens, in combination with a healthy active lifestyle, does not generally result in vitamin D deficiency.

# A healthy lifestyle

Maintaining a healthy lifestyle by keeping up-to-date with follow-up appointments, being active, eating a balanced diet and getting enough rest is important for your physical and emotional health.

## Maintain your follow-up visits

Keep up-to-date with your scheduled follow-up visits and monitor your general health.

## Exercise

Exercise can have a positive effect on your body and wellbeing. Try to be active most days of the week, everyday if you can manage, aiming for 2½ to 5 hours of moderate activity each week. In the beginning it is important you do not push yourself too hard and listen to your body's signals. A physiotherapist or a personal trainer can help you set up an exercise program that suits your body and needs.

## Rest

Be realistic about how active you can be immediately following your treatment. If your treatment involve extensive surgery, you will need time to heal.

## Diet

Having a good, nutritionally-balanced diet is important to maintain your energy, mood and health. Fresh vegetables, fruit, nuts, lean meat, fish, wholegrains and non-processed food are a good start to a healthy diet. Limit your consumption of alcohol, sugar and saturated fats.

Discussing your diet with a dietitian can be helpful. Some dietitians specialise in providing advice to people affected by cancer. Talk to your healthcare team or contact the Dietitians Association of Australia for a recommendation on a suitable dietitian for you.

Exercise is  
Medicine  
Australia



[exerciseismedicine.org.au/public](http://exerciseismedicine.org.au/public)

Find an accredited  
exercise  
physiologist at



[essa.org.au](http://essa.org.au)

## Smoking

Researchers have found that melanoma patients who smoke have an increased risk of their disease progressing compared to patients who do not smoke. In addition, smoking has been shown to reduce the blood flow necessary for normal wound healing following surgery. It is recommended to stop smoking.

### Dietitians Association of Australia

[daa.asn.au](http://daa.asn.au)  
1800 812 942



### Nutrition and Cancer

Resource available  
from Cancer Council:  
[cancercouncil.com.au](http://cancercouncil.com.au)  
13 11 20



### Quitline

If you need help  
quitting, contact the  
Quitline on 13 7848 or  
visit [quitnow.gov.au](http://quitnow.gov.au)



# Coping and emotional wellbeing

Everyone deals with diagnosis and treatment of melanoma differently. You may feel it is a minor concern or you may find it impacts on many aspects of your life.

Whether you experience fear or anger over the diagnosis, uncertainty about treatment decisions or even happiness and hope when things are going well it is important for your emotional health to acknowledge and express your feelings.

If you find that the way you feel is starting to interfere with the way you want to live your life, if you experience anxiety, stress or even depression, then it is important you talk to your healthcare team to get help early.

There are programs, support groups and helplines that can be very useful. Professionals such as counsellors and psychologists can provide you with strategies to help you cope with your situation. Your healthcare team can link you to appropriate support and your GP can arrange Medicare cover for seeing a psychologist.

## Living Well After Cancer

Resource available from Cancer Council:  
[cancercouncil.com.au](http://cancercouncil.com.au)  
13 11 20



## Emotions and Cancer

Resource available from Cancer Council:  
[cancercouncil.com.au](http://cancercouncil.com.au)  
13 11 20



# Seeking support

Support groups are available for people with melanoma, their families and friends.

Sharing your melanoma experience with someone who has had a similar experience can be really helpful. Support groups offer a safe environment for patients and their loved ones to talk about their concerns and support each other along the way. They can be a great source of information and comfort to patients, their family and friends.

## Melanoma Institute Australia

**melanoma.org.au**  
(02) 9911 7200

Melanoma Institute Australia support groups are run monthly in a range of NSW locations.

## Melanoma Patients Australia

**melanomapatients.org.au**  
1300 884 450

Melanoma Patients Australia offers a range of support services across Australia including face-to-face support groups, closed Facebook support groups, phone support groups and counselling.

## melanomaWA

**melanomawa.org.au**  
(08) 9322 1908

melanomaWA hold monthly meetings throughout Western Australia, as well as offering one-on-one support, phone support and peer-to-peer support.

### Support is not the same for everyone

For some people, the idea of seeking support may seem uncomfortable, silly or even a little scary. It may be that you just want more information; you may want to talk to someone who has been in your shoes or you might want to know what is available in case you need support later.

Access to information and support will differ according to where you live and will vary according to your needs, whether it is financial, practical, emotional or informational. With the range of services available online and in-person, you will be able to find something that suits your situation. Help is available, if you need it.

### Cancer Council Australia

**cancer.org.au**

Cancer Council Helpline: 13 11 20

Cancer Council provides a confidential telephone information and support service that anyone can call. This includes people recently diagnosed with cancer, those previously treated and living with cancer, their families, friends, carers, teachers, students and health professionals.

### Cancer Council Online Community

The Cancer Council Online Community offers a safe and supportive online discussion site for people affected by cancer, their carers and families.

### Cancer Connect

This Cancer Council service is a confidential telephone peer support service that connects someone who has cancer with a specially trained volunteer who has had a similar experience.

### Other useful websites

American Cancer Society

**www.cancer.org**

MD Anderson Cancer Center

**mdanderson.org**

MacMillan Cancer Support

**macmillan.org.uk**

# Information and support for loved ones

A cancer diagnosis can also affect your partner, children, family and friends. It can help for your loved ones to seek support during this time.

## Young people

Parents can feel overcome by their own fears with their diagnosis and their first impulse may be to protect their children from these same emotions. But most children sense that something is wrong even if they don't know what it is. Resources are available to help you have a discussion with your children to help them understand and receive the news in the best possible way.

### Talking to kids about cancer

Booklet available from  
Cancer Council

[cancercouncil.com.au](http://cancercouncil.com.au)

13 11 20



## CanTeen

Information for young people  
between the ages of 12-25

'Dealing with your parent's cancer' booklet  
available

[canteen.org.au](http://canteen.org.au)

1800 835 932

## Carers

### Caring for someone with cancer

Resource available from Cancer Council

[cancercouncil.org.au](http://cancercouncil.org.au)

13 11 20

## Carers Australia

[carersaustralia.com.au](http://carersaustralia.com.au)

(02) 6122 9900

## Young Carers

[youngcarers.net.au](http://youngcarers.net.au)

1800 242 636





# Your melanoma organiser

The melanoma organiser has been designed to accompany you through your care and help you to keep track of what is going on.

It is hoped that you will find this section a useful way to keep track of important information in the one place.

# Personal details

Name .....

Address .....

City ..... State ..... Postcode .....

Phone ..... Mobile .....

Email .....

## In case of emergency

### Emergency contact 1

Name .....

Address .....

City ..... State ..... Postcode .....

Phone ..... Mobile .....

Relationship .....

### Emergency contact 2

Name .....

Address .....

City ..... State ..... Postcode .....

Phone ..... Mobile .....

Relationship .....

### Healthcare cards

Medicare card number .....

Expiry .....

Healthcare concession card number (if applicable) .....

Expiry .....

Health insurance company (if applicable) .....

Policy number..... Level of cover .....

### Patient identification numbers

INSTITUTION/HOSPITAL	PATIENT IDENTIFICATION NUMBER
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# My diagnosis summary

If you find it helpful you can record details of your diagnosis here. Ask your doctor to help you fill in the following information.

Date of biopsy .....

Doctor who took the biopsy .....

Location/s on my body .....

## Results

Breslow thickness (mm) .....

Level of invasion (Clark) .....

Ulceration  Yes/present  No/absent

Mitotic rate .....

You may require further investigations such as blood tests, ultrasounds, scans or a sentinel node biopsy in order to stage the melanoma or to determine your treatment approach.

Sentinel Node Biopsy .....

My melanoma is Stage .....

Your doctor may talk to you about a test that looks for changes (mutations) in the DNA code of your melanoma. The test itself can be conducted using tissue removed during your surgery.

BRAF status ..... mutant/positive ..... wild-type/negative

NRAS status ..... mutant/positive ..... wild-type/negative

cKIT status ..... mutant/positive ..... wild-type/negative

You may wish to ask for copies of your pathology reports. Simply request them from your doctor.

# My treatment plan

## Surgery

Date of wide excision .....

Surgeon/Doctor .....

Hospital .....

Contact number .....

## Pre-operative instructions

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## Post-operative instructions/wound care

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## Date for removal of stitches and follow-up

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**Pathology results**

Lymph node dissection needed  Yes  No

Number of lymph nodes removed .....

**Notes on surgery**

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**Radiation therapy**

Planned?  Yes  No

Radiation oncologist .....

Radiation received at .....

Contact number .....

Number of treatments planned .....

Start date..... Finish date .....

Number of treatments received .....

Dose received .....

Areas treated

.....  
.....  
.....

Notes on radiation therapy

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### Systemic therapy

(immunotherapy, targeted therapy)

Date of treatment .....

Type of treatment .....

Doctor .....

Purpose of treatment .....

Notes .....

.....

Date of treatment .....

Type of treatment .....

Doctor .....

Purpose of treatment .....

Notes .....

.....

Date of treatment .....

Type of treatment .....

Doctor .....

Purpose of treatment .....

Notes .....

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Date of treatment .....

Type of treatment .....

Doctor .....

Purpose of treatment .....

Notes .....

Date of treatment .....

Type of treatment .....

Doctor .....

Purpose of treatment .....

Notes .....

Date of treatment .....

Type of treatment .....

Doctor .....

Purpose of treatment .....

Notes .....

### Clinical trials

Planned  Yes  No

#### Notes

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### Supportive care

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### Complementary therapies

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# My follow-up plan

## Tests or visits

### Clinical skin examinations

How often? .....

Doctor .....

### Self examination

I will check my own skin every  months

If I am concerned about my scar/skin, I should contact

.....  
.....

### Scans

Which scans? .....

How often? .....

Doctor .....

### Blood tests

How often? .....

Doctor .....

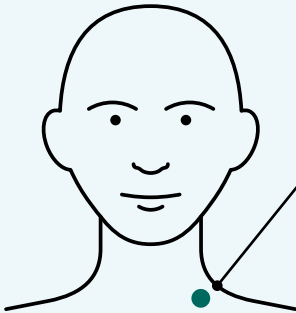
### Notes

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.....  
.....

# Body maps

Use the body maps on the following pages to mark any number of lesions that you want to keep an eye on over time. The image below provides an example of how you can monitor a mole over time.

## Example



1/01/2018 – new, 2mm, brown

4/01/2018 – checked by doctor

1/04/2018 – no change

1/07/2018 – changed: 3mm,  
red spots, needs checking by doctor

Use the size guide to measure the size of a mole or lesion that you are monitoring. Mark the size of the mole or lesion on your body map.

## Size Guide

3mm



5mm



7mm



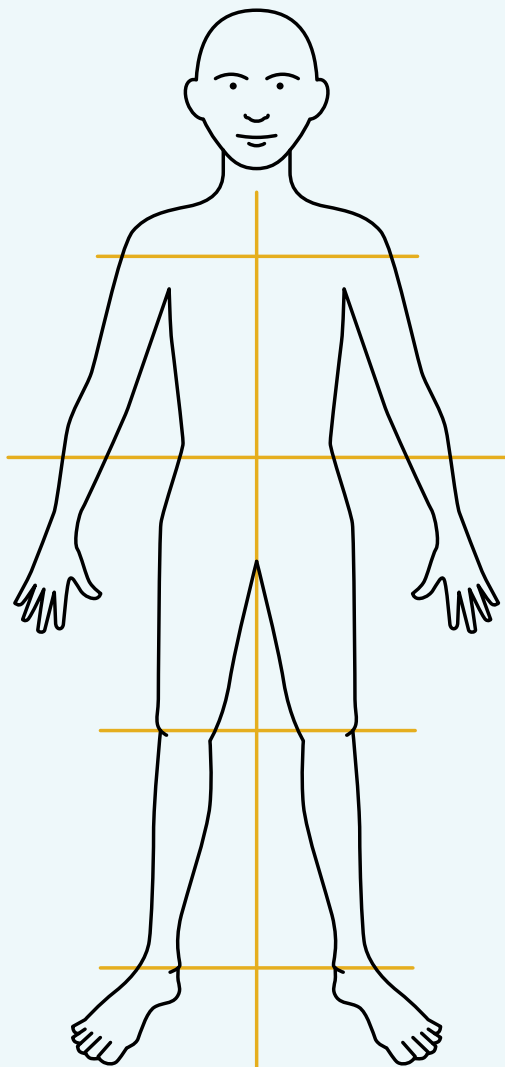
9mm



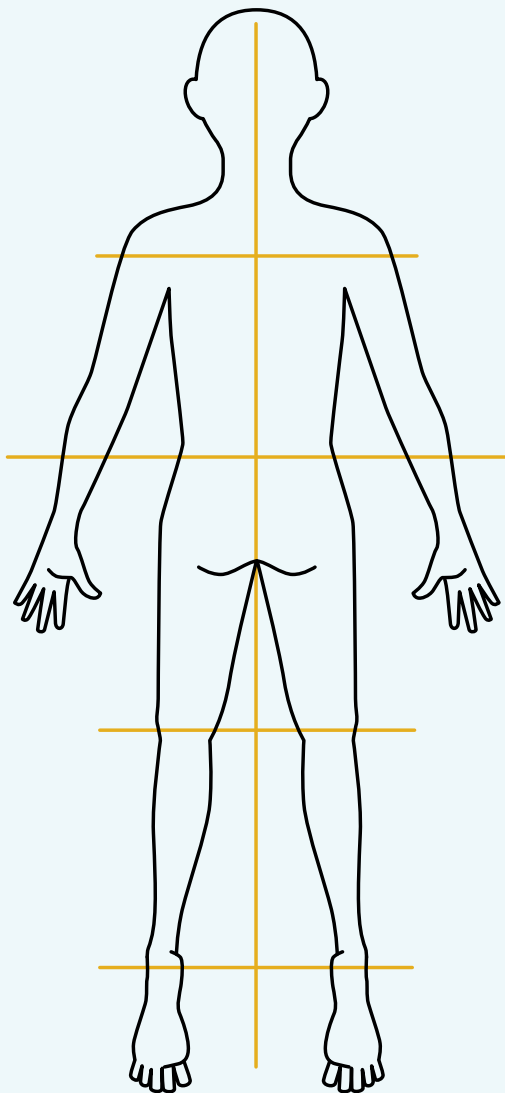
11mm



## Body Map







# My healthcare team

A multidisciplinary team is a group of health professionals from different specialities who form your healthcare team.

You might not need to see all of these people, but it can be helpful to know what different health professionals do.

## General practitioner

A doctor who manages your screening, diagnosis, general health needs. Your GP may be involved in co-ordinating your care and follow-up.

## Dermatologist

A doctor who specialises in the diagnosis, treatment and prevention of skin disease and skin cancers.

## Pathologist

A doctor who specialises in examining tissue to see whether a sample has normal or diseased cells.

## Surgeon

A doctor who operates to remove the melanoma.

## Plastic surgeon

A doctor who specialises in reconstructive surgery.

## Medical oncologist

A doctor who specialises in managing cancer with systemic (drug) therapies, such as immunotherapy and targeted therapy.

## Radiation oncologist

A doctor who specialises in the use of radiation therapy to manage cancer.

## Clinical Nurse Consultant

A specialised nurse who provides you, your family and your doctors with advice, support and care.

## Clinical trials co-ordinator

A person who manages the needs of the trial and your medical needs while you are on the trial.

## Oncology social worker

A person who can help you with practical information and support, and can link you to community resources.

## Psychologist

A person who can provide support and strategies to help you overcome emotional problems.

## Physiotherapist

A person who can help with physical recovery from injury or improving mobility, especially for people who have lymphoedema.

## Palliative care team

A team who can help improve quality of life and provide support to you and your family.

Name .....

Occupation/Department .....

Address .....

..... Postcode .....

Phone..... Mobile .....

Notes .....

Name .....

Occupation/Department .....

Address .....

..... Postcode .....

Phone..... Mobile .....

Notes .....

Name .....

Occupation/Department .....

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Notes .....

# My Appointments

Appointment with .....

Date ..... Time .....

Location .....

Reason for appointment .....

Notes .....

Appointment with .....

Date ..... Time .....

Location .....

Reason for appointment .....

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Appointment with .....

Date ..... Time .....

Location .....

Reason for appointment .....

Notes .....

Appointment with .....

Date ..... Time .....

Location .....

Reason for appointment .....

Notes .....

# Medication chart

Keep track of your medication using the chart below.

It is a good idea to review your medication with your healthcare team from time to time.

MEDICATION	DIRECTIONS	NOTES
<i>Maxolon</i>	<i>Take 1 tablet 1 hour before food</i>	<i>For nausea</i>



MORNING	MIDDAY	AFTERNOON	EVENING
<i>As needed</i>			

# Medical expenses

DATE	DOCTOR, HOSPITAL OR SERVICE PROVIDER	TYPE OF SERVICE (E.G. TEST, PATHOLOGY, CONSULTATION)

COST OF SERVICE	DATE CLAIM SENT	MEDICARE OR HEALTH INSURANCE	DATE REBATE RECEIVED	AMOUNT RECEIVED	OUT OF POCKET AMOUNT

# My notes and questions

## Getting the best information from your healthcare team

Take someone with you to appointments. It's always handy to have someone else there to hear what the doctors are saying.

Be prepared. Write down your questions before appointments and take note of the answers. Use this book to keep everything together and take it to all of your appointments.

Remember, it's always ok to ask for information about your care.

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A series of horizontal dotted lines spanning the width of the page, intended for handwritten notes or organizing information.



A series of horizontal dotted lines for writing notes.

# Glossary

Here are some words that may be new to you. Add in other terms that you are unsure about and ask your health professionals to provide you with a clear definition.

## Adjuvant

Additional treatment that is used to increase the effectiveness of the main treatment (e.g. radiation therapy following surgery).

## Atypical moles

Unusual looking but non-cancerous moles. Having atypical moles can be a risk factor for melanoma.

## Benign

Not cancerous.

## Biological therapy

Treatment that uses substances made naturally by the body, or that change chemical processes in cancer cells. This includes immunotherapies and targeted drugs.

## Cutaneous melanoma

Melanoma that starts in the skin.

## Dermis

The skin is made up of two layers; the dermis is the inner layer that contains hair roots, sweat and oil glands, nerves, blood and lymph vessels.

## Epidermis

The epidermis is the outermost layer of the skin. It covers the dermis.

## In-situ

The melanoma is confined to the cells in the top layer (epidermis) of the skin. The melanoma has not invaded deeper layers (dermis).

## Lesion

A lesion is a general term for anything abnormal such as a cut, injury or tumour.

## Malignant

Cancer.



### Melanocytes

These are cells that produce melanin which gives skin its colour. These cells are found in many places in our body, including the skin, hair, eyes and the mucous membranes (such as the lining of the mouth, nose, and other internal structures of the body).

### Melanoma

Cancer of the melanocytes. While usually developing on the skin, melanoma can also affect internal structures of the body.

### Metastatic melanoma

Cancer has spread from where it started (primary site) to another part of the body (secondary cancer).

### Nevus

Another term for mole, birthmark or beauty spot.

### Prognosis

The likely outcome or course of a disease.

### Recurrence

Return of the cancer anywhere. A local recurrence is the return of the cancer at the original site.

### Sentinel node biopsy

Removal and examination of the first lymph node to receive lymph fluid from a tumour.

### Systemic therapy

Treatment using substances that travel through the bloodstream to reach cells all over the body.

### Tumour

A tumour is an abnormal growth of cells.

### Ulceration

The breakdown of the skin over the melanoma. This may be visible only with a microscope (i.e. in the pathologist's report).

### Wide local excision

The surgical removal of the melanoma along with some normal tissue around it (a margin) to ensure that all cancer cells are removed.

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