

# Your Guide

to Early Melanoma



Melanoma  
Institute Australia



The contents of this guide are personal and confidential.  
If found, please contact:

Name .....

Mobile .....

Email .....



# The purpose of this guide

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

This guide provides general information to help answer your questions about 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.

This guide can:

- Help you 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.
- Help you prepare for follow-up and the future.

## Note to reader:

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

## Who is this guide for?

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

# Contents

|                                                    |           |                                                              |           |
|----------------------------------------------------|-----------|--------------------------------------------------------------|-----------|
| <b>About melanoma</b> .....                        | <b>3</b>  | <b>Self-care and support during and after melanoma</b> ..... | <b>39</b> |
| What is melanoma?.....                             | 4         | Looking after yourself.....                                  | 40        |
| The skin.....                                      | 5         | Your emotional wellbeing.....                                | 43        |
| How cancer grows and spreads.....                  | 6         | Getting help and support.....                                | 53        |
| What is early stage melanoma? .....                | 8         | Your family and friends.....                                 | 57        |
| <b>Diagnosing and treating melanoma</b> .....      | <b>9</b>  | <b>Your melanoma organiser</b> .....                         | <b>61</b> |
| Initial diagnosis .....                            | 10        | My diagnosis summary .....                                   | 62        |
| Pathology results .....                            | 11        | My treatment summary .....                                   | 64        |
| Staging melanoma .....                             | 16        | My follow-up plan .....                                      | 66        |
| Prognosis .....                                    | 18        | My healthcare team .....                                     | 70        |
| Treatment .....                                    | 19        | My appointments .....                                        | 73        |
| <b>Follow-up care</b> .....                        | <b>27</b> | My notes and questions.....                                  | 75        |
| Self examination.....                              | 30        | <b>Glossary</b> .....                                        | <b>80</b> |
| Understanding your risk factors for melanoma ..... | 33        |                                                              |           |
| Sun protection .....                               | 34        |                                                              |           |
| Vitamin D .....                                    | 37        |                                                              |           |

# 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 AO and Professor Richard Scolyer**  
Co-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.

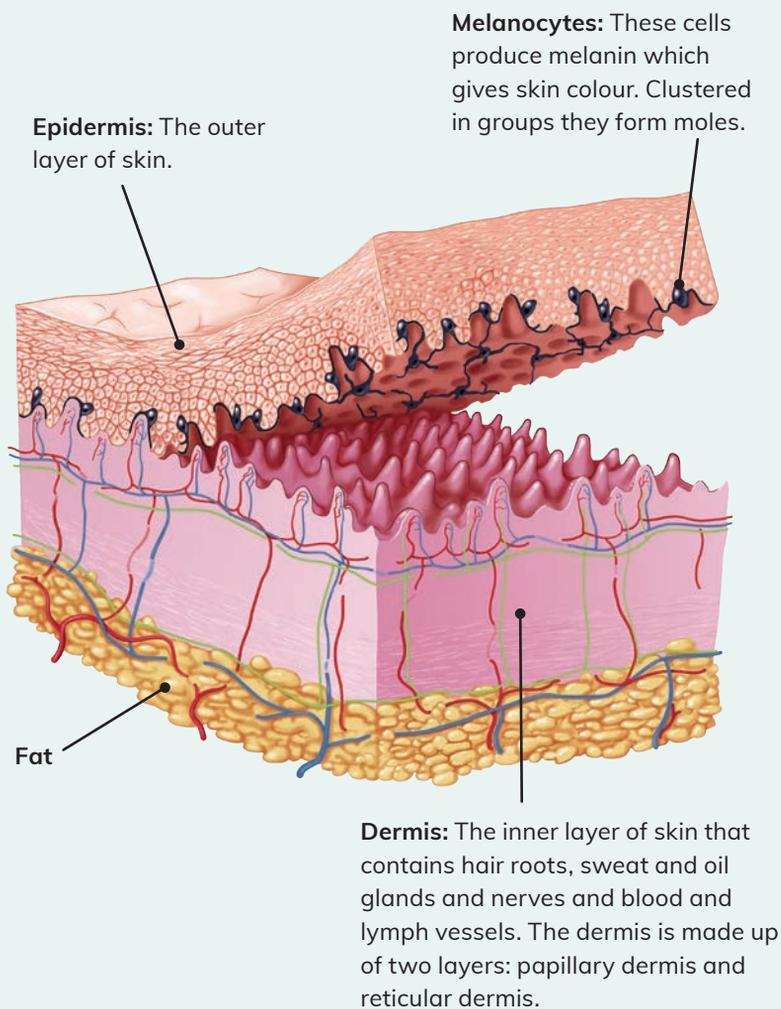
Australia has one of the highest rates of melanoma in the world.

More than 15,000 new cases of melanoma are diagnosed every year in Australia. Of these, 90% of people will be treated successfully by having the primary melanoma surgically removed.



On average, 42 Australians will be diagnosed with melanoma every day; that is close to one diagnosis every half hour.

# The skin

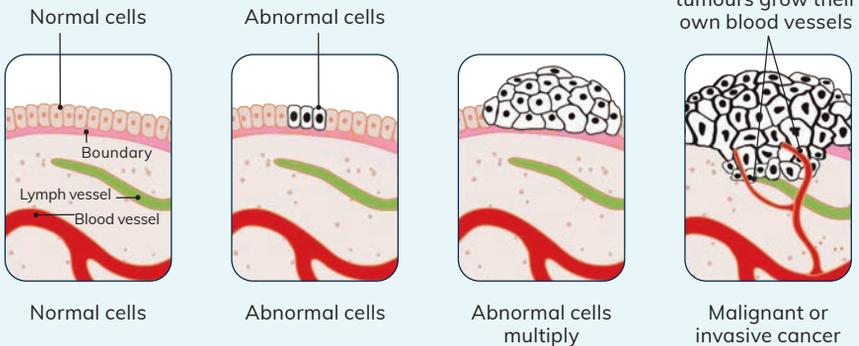


# How cancer grows and spreads

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.

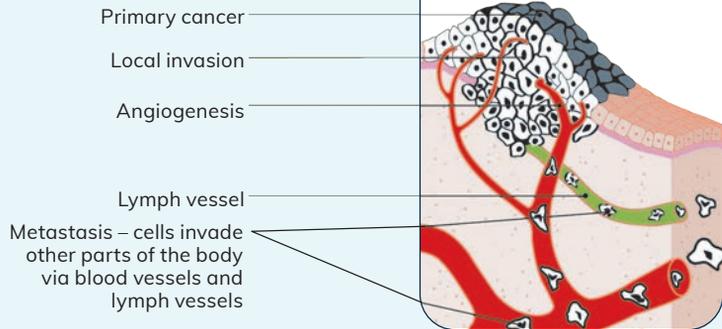
Cancer occurs when abnormal cells grow and divide in an uncontrolled manner, forming a tumour.

## 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 system. This process is called metastasis.

### How cancer spreads



Adapted from Cancer Council Victoria. Illustration by Paul Sloss.

# What is early stage melanoma?

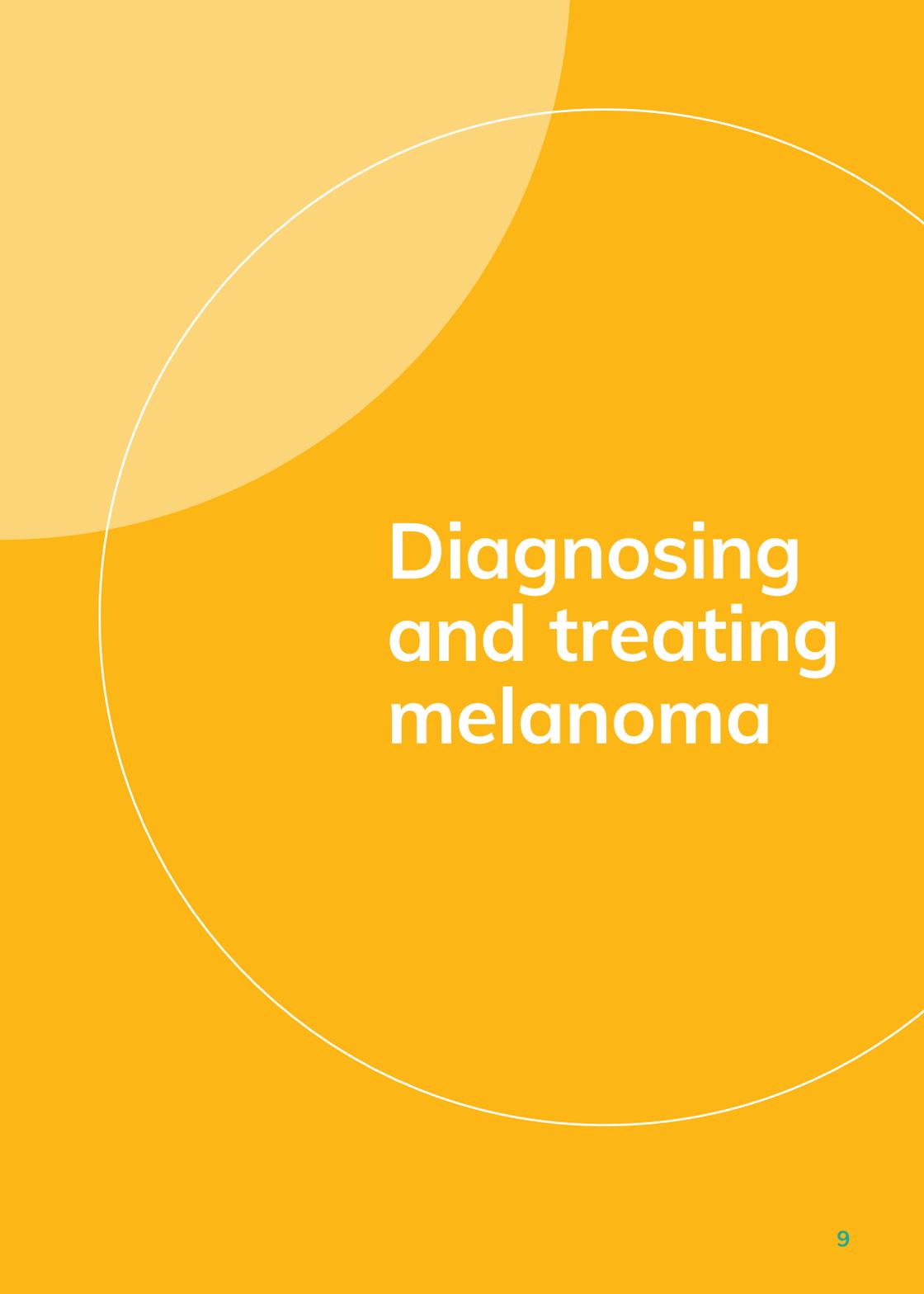
The stage of a cancer is used to describe its size and whether it has spread to other parts of the body. Melanoma can be described as Stage 0, I, II, III or IV.

Early stage melanoma refers to Stage I or II. This means the melanoma is confined to the layers of skin where it started and it has not spread to nearby lymph nodes. Early stage melanoma is also known as localised melanoma.

Stage 0 is very early stage melanoma, also known as in-situ melanoma. This means the melanoma is confined to the top layer of skin (epidermis) and has not spread to the deeper layer of skin (dermis). Lentigo Maligna (Hutchinson's melanotic freckle) is a type of in-situ melanoma.

You can read more about each stage of melanoma on pages 16-17.

Treatment for melanoma depends on a number of factors, including stage. You can read more about treatment for melanoma on pages 19-23.



# Diagnosing and treating melanoma

# Initial diagnosis

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.

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 over the next few pages. You may like to use the blank report on page 63 to record your pathology results. You can ask your doctor to help you fill this in.



# 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

(You can fill in your own pathology results on page 63)

**Patient name:** SMITHSON, Mary  
**DOB/Sex:** 1/01/1951, F  
**Requested by:** Dr Jackson, Sally  
**Requested on:** 01/05/2020  
**Specimen received:** 02/05/2020

### PATHOLOGY REPORT

#### CLINICAL DETAILS

Suspicious pigmented lesion, left thigh.

#### MACROSCOPIC

A skin ellipse measuring 25x15mm of 5mm depth with an irregularly pigmented blue black macule spanning 6x4mm.

#### MICROSCOPIC REPORT

Specimen type: Excision

Site: Left thigh

Diagnosis: Melanoma

Classification/Main pattern: Superficial spreading

Thickness: Breslow 0.7mm

Clark level: III

Ulceration: Absent

Dermal mitoses: Not seen (0/mm<sup>2</sup>)

Margins of excision:

- Invasive component to nearest peripheral margin: 1.0 mm
- Insitu component to nearest peripheral margin: 2.0 mm

#### SUMMARY

Skin left thigh, excision, 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.

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 1 mm    | Thin melanoma                   |
| 1–4 mm            | Intermediate thickness melanoma |
| Greater than 4 mm | 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<br>(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              | <b>Melanoma can be up to 2 mm in thickness without ulceration; or up to 1 mm in thickness with ulceration.</b>                                                                            | <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             | <b>Melanoma can be over 2 mm in thickness without ulceration; or 1 mm to &gt;4 mm in thickness with ulceration and no lymph node spread.</b>                                              | <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 III            | Melanoma has spread to local lymph nodes or nearby tissues (in-transit disease).                                                                                                          | <ul style="list-style-type: none"> <li>– Surgical removal (wide local excision) for in-transit disease</li> <li>– Consideration of lymph node dissection (removal of all lymph nodes in the affected region)</li> <li>– Consideration of additional treatments before or after surgery, such as radiation therapy or drug (systemic) therapies</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>                                                                                                                                                                                                           |

# 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 find it helpful to talk to a professional, such as a counsellor or psychologist, about your response to finding out about your prognosis. You can read more about accessing this support on page 53.

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

# Treatment

## Surgery

A primary melanoma always requires surgical removal. This surgery is called a wide local excision. It involves removal of the melanoma or scar from 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. 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.

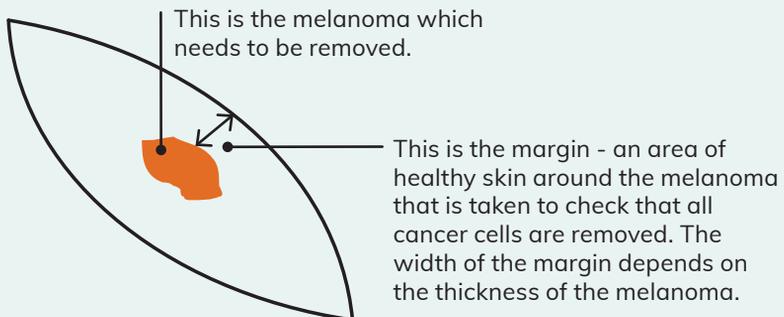
The wide local excision can be performed as a day procedure using local anaesthetic although some people will require a general anaesthetic or a hospital stay.

A wide local excision is standard treatment for in-situ, Stage I and Stage II melanomas.

For some people, a wide local excision may be the only treatment necessary.

### Wound care

How you care for your wound will depend on the size and the location of the excision and whether or not a skin flap or skin graft is required. Your doctor or nurse will advise you about dressing changes, healing time and whether you need stitches or staples removed.



### Side effects from surgery

Some common but manageable side effects following surgery are pain, infection and scarring. If you do experience pain make sure you ask for pain relief. Depending on the location and size of the excision, and whether a skin flap or skin graft was necessary, you may also experience some inflammation and reduced mobility for the first few weeks after surgery. Monitor your side effects and if you feel in any way uncomfortable seek medical advice. Occasionally a referral to a physiotherapist may be required but this should be discussed with your doctor.

### Scars

You will have a scar after your surgery. Everyone scars differently depending on skin type and how invasive the surgery was. Infections and wound complications can also alter the appearance of the scar. After surgery your scar will look red and raw; this will eventually settle and your scar will fade with time. Once the wound is healed, you may use creams and topical ointments to minimise the appearances of the scar. These topical treatments can help reduce the appearance but will not make the scar go away completely.

### Patient Information Brochures



#### Melanoma

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

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

### Optimal Care Pathway



Cancer Council has developed an online resource to help you understand what comes next on your melanoma pathway. It outlines the optimal care that should be provided each step of the way.

[cancerpathways.org.au/  
optimal-care-pathways/  
melanoma](http://cancerpathways.org.au/optimal-care-pathways/melanoma)

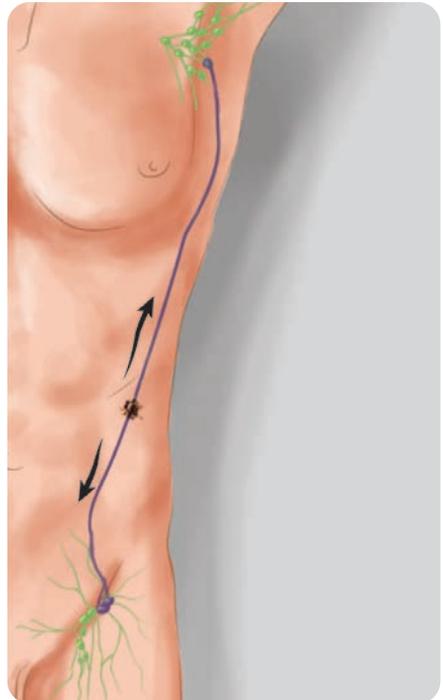
## Sentinel node biopsy

A sentinel node biopsy may be discussed if the results of your initial biopsy indicate that your melanoma has a moderate-to-high risk of spreading.

This procedure is usually performed at the same time as the wide local excision, to check if the melanoma has spread to nearby lymph nodes.

Lymph is fluid that escapes from blood vessels into the tissues. It moves through your body in its very own system of lymphatic vessels. This lymph fluid carries oxygen and nutrients to tissues throughout your body and also carries waste to be filtered by your lymph nodes or glands. Lymph nodes are found along lymphatic vessels and are important to your body's immune response to infection.

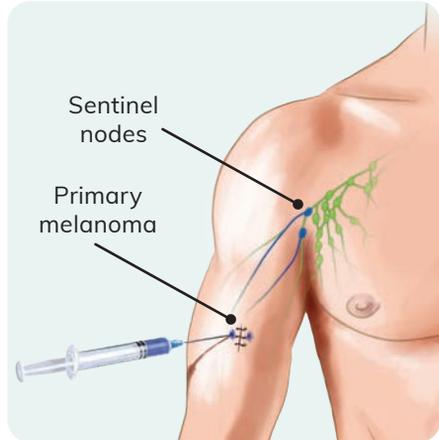
The sentinel node is the first lymph node or nodes that filter lymphatic fluid from the area of skin that has melanoma. If the cancer has spread, the sentinel node is the most likely node to have cancer in it.



To find the sentinel node, a radioactive dye is injected around the area of skin near the primary melanoma. The dye maps the lymphatic vessels in the area and shows the number and 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 need to discuss further treatment which may include regular ultrasound to determine if other lymph nodes are involved, complete lymph node dissection, where all lymph nodes in the affected area are removed, or drug therapy.



**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)



## Adjuvant therapies

After the main treatment for a melanoma, which is usually surgery, other treatment can be given to reduce the risk of the melanoma coming back in the nodes or spreading to other parts of the body. This is known as adjuvant therapy.

Adjuvant therapy is not usually offered for treatment of Stage I or II melanoma but may be recommended in particular circumstances.

## Radiotherapy

Radiotherapy following a lymph node removal is an example of how radiation can be used as an adjuvant therapy. Radiotherapy uses radiation in the form of x-rays to kill cancer cells or to damage them so they do not multiply. Radiotherapy may also be used to control cancer growth or spread, or to relieve symptoms to make people more comfortable.

## Targeted therapies and immunotherapies

Targeted therapies are drugs that identify and attack or block specific parts of the cancer cell. Immunotherapies work by activating the body's own immune system to fight the melanoma cells. At this time targeted therapies and immunotherapies are not standard care for the treatment of early stage melanoma.

## Clinical trials and research

Having been diagnosed with melanoma, you may be offered participation in a clinical trial or a research study. Clinical trials are conducted to help find better ways to prevent, screen, diagnose or treat a disease or to improve the quality of life of those who have this disease.

### Understanding Radiation Therapy

Resource available from Cancer Council

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

13 11 20



## What is the role of complementary or alternative therapies?

Some people may choose to use complementary therapies **alongside** conventional treatments to maintain a sense of wellbeing, manage side effects or for general health purposes. These therapies may include meditation, massage, vitamins, special diets and yoga.

Alternative therapies are used **instead of** conventional treatments. Alternative therapies are unproven and have not been scientifically tested. They may cause harm or increased risk to those who use them instead of conventional treatments. If you are thinking about using alternative therapies speak to your doctor first.

### Understanding Complementary Therapies

Resource available from Cancer Council

[cancercouncil.com.au](http://cancercouncil.com.au)  
13 11 20



### Massage and Cancer

Resource available from Cancer Council

[cancercouncil.com.au](http://cancercouncil.com.au)  
13 11 20



## When should my care be managed by a specialist melanoma centre?

Early stage melanoma can be managed by a GP or a dermatologist. There are some occasions where you may be referred to a specialist melanoma centre. Some reasons include:

- a thin melanoma on a part of the body that is difficult to operate on (e.g. the face or lower legs)
- an intermediate thickness melanoma when a discussion about sentinel node biopsy is recommended
- when the referring doctor is uncertain of treatment in any way.

When someone has had multiple melanomas or they have what is called Atypical Naevus Syndrome (more than one close family member who has had

melanoma and many dysplastic or unusual looking moles) they may also be referred to a specialist centre.

## What happens if the cancer comes back or spreads?

For most people, surgery is a successful treatment for melanoma. In some cases, however, the melanoma can come back (recur) or spread to other parts of the body. If the disease progresses this is called advanced melanoma. There are treatment options for advanced disease and further information and resources are available.

If you are concerned about the cancer coming back, speak to your doctor.





# 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 a physical examination with their GP or dermatologist, others may see their surgeon. In some cases follow-up care is shared between two doctors.

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 can be detected early.

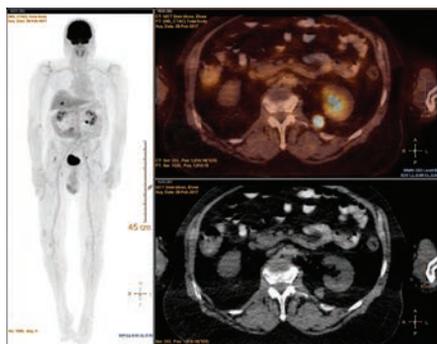
This physical examination may be aided by the use of total body photography to detect any changes in your skin.

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.

Your doctor will encourage you to participate in your follow-up care by examining your skin for potential melanoma. During these skin checks, you should also look for any abnormal lumps, especially where the surgery was done and in nearby lymph nodes. The 'ABCDE' rule on page 30 gives some information about what a melanoma commonly looks like.

### Follow-up scans

Imaging or scans may be recommended as part of your follow-up. These 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 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)** scans use 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)** scans show 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).
- **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)

### A Asymmetry

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



### B Border irregularity

Watch for spots that have an irregular, ragged, notched or ill-defined **border**.



### C Colour variation

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



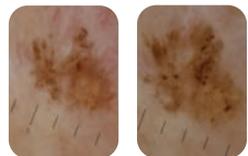
### D Diameter

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



### E Evolution

Look for **new marks**, freckles or moles. Be on the lookout for **changes** in existing spots, freckles or moles, including changes in size, shape, colour, elevation, or another trait (such as itching, bleeding or crusting).



Some spots may not show any of the 'ABCDE' signs. For example, amelanotic melanoma is a type of melanoma 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 in that area for any new lumps.

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

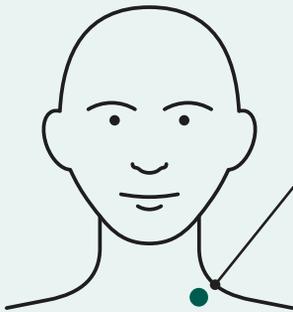
If you notice any of the signs described here, see your doctor as soon as possible.

**Squamous Cell Carcinomas and Basal Cell Carcinomas** are other types of skin cancer. 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 68 and 69 along with the date and any comments.

### Example



1/01/2020 – new, 2 mm, brown

4/01/2020 – checked by doctor

1/04/2021 – no change

1/07/2021 – changed: 3 mm,  
red spots, needs checking by  
doctor

Apps for mobile devices such as 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.



# 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 – 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, 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 fact sheet.



[genetics.edu.au](https://genetics.edu.au)  
Search for 'Fact sheet 34 - Genetics and Melanoma'

# Sun protection

It is important to protect yourself from the sun, even after you have been diagnosed with melanoma. Some treatments for melanoma can make your skin more sensitive to the sun. It is important to discuss appropriate sun protection with your healthcare team, and to follow the five sun safe rules:



Seek shade, especially in the hottest part of the day



Wear sun-protective clothing that covers your back, shoulders, arms and legs



Wear a broad-brimmed hat



Apply a broad-spectrum sunscreen with an SPF of at least 50+ every 2 hours and after swimming or exercise



Wear wrap-around sunglasses

## Understanding UV

Did you know that 95% of melanomas are caused by exposure to ultraviolet (or UV) radiation?

Light from the sun contains UV radiation which can damage your skin. It's important to remember that UV can't be seen or felt, and cloud cover won't necessarily reduce UV radiation levels.

The UV index is a tool you can use to know when to protect yourself from UV radiation. When the UV index is 3 and above sun protection is always needed.

## Choosing sunscreen

Choose a sunscreen with the highest possible SPF rating (currently SPF50+ in Australia) and broad spectrum UVA and UVB protection.

## 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).

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.

For spray products, hold the nozzle close enough to ensure the spray reaches your skin and keep spraying until your skin is glistening. Spread gently to ensure even coverage and then let the product absorb. Ensure you apply spray sunscreen out of the wind otherwise the product may blow away before it reaches your skin.

## 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.

## 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 collared shirts.

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



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

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

# Vitamin D

## What do I need to know about vitamin D?

Vitamin D is important for bone health and regulating the immune system. Vitamin D is best absorbed by the body when exposing the skin to sunlight. We also get small amounts of vitamin D from some food sources such as milk, eggs and fatty fish.

## Does sunscreen use prevent vitamin D production?

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

## How do I get it and what's the right amount for me?

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.

Vitamin D requirements will change with age, skin type, season, geographic location, and pregnancy. If you have questions about your vitamin D levels, talk to your doctor. Vitamin D levels can be checked with a blood test and if levels are low, it may be recommended that you take a supplement.

Keep an eye on the UV index in your area by downloading the SunSmart app on your phone or look for the UV rating on some weather apps. It tells you when sun protection is needed in your local area.





# Self-care and support

During and after  
melanoma

# Looking after yourself

Maintaining a healthy lifestyle is important for both your physical and emotional wellbeing during and after melanoma treatment.

From being active and eating well to participating in activities you enjoy, it's time to put yourself at the top of your priority list!

## Maintaining your follow-up visits

Be sure that you keep up to date with your scheduled follow-up visits and closely monitor your general health. Record details of your follow-up plan and appointments in the personal record section at the end of this Guide, from page 61.

## Keeping active

Being physically active and exercising regularly is important for your physical health, your emotional wellbeing and your quality of life.

Try to be active most days of the week – every day if you can manage. In the beginning, start slowly and listen to your body. When you feel ready, work up to doing 30 minutes of aerobic activity on three or more days of the week.

This may include activities like walking, jogging, swimming or cycling. Aim to be working at a pace where you can talk but not sing.

## Patient Information Brochures on Exercise

Melanoma Institute Australia has developed a series of helpful patient information brochures on exercising after neck, axillary and groin or pelvic dissection. If you have undergone a dissection procedure, you can download the relevant brochure/s from [melanoma.org.au](http://melanoma.org.au).



You should also incorporate two to three resistance exercise sessions during the week. This may include lifting weights or using your body weight as resistance in exercises such as squats, lunges and push-ups.

If you have had surgery, be mindful of your surgical site and move within the recommendations of your healthcare team. The aim is to reap the benefits of exercise without incurring injury.

Speak to your treatment team about referral to an accredited physiotherapist or exercise physiologist, who can help you set up an exercise program that suits your body and needs.

## Eating well

Eating a fresh, nutritionally balanced diet can help you to maintain your energy and keep you feeling good during and after treatment for melanoma.

Choose fresh vegetables, fruit, nuts, lean meat, fish and non-processed foods. Drink 6 cups of water each day to keep hydrated.

Sometimes treatment can affect your appetite and change your relationship with food. It can be helpful to talk to a dietitian to help you stay nourished and strong.

You can find an accredited practising dietitian through the Dietitians Australia at [daa.asn.au](http://daa.asn.au) or on **1800 812 942**. The 'Find an accredited practising dietitian' button on the website allows users to search for dietitians with a specialty in cancer.

## Resting and recuperating

You will need time to rest and heal following treatment for melanoma – especially if your treatment involved extensive surgery.

Be realistic about how much you can do immediately following your treatment. You may have good days and bad days. Don't push yourself to do too much, too soon, even if you feel well. Take your time to rest and recuperate so that you can get back to the things you enjoy the most without unnecessary setbacks.

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



A good sleep routine is an essential element in your recuperation. Go to bed at the same time each night and wake up at the same time each day. Avoid caffeine and electronics, such as your phone, television or computer, close to bedtime. Instead, relax with a good book or some soft, calming music.

## Doing activities that you enjoy

When you are feeling overwhelmed or stressed, it can be helpful to have something to look forward to. Making plans to do activities that you enjoy – like going out for a special meal or socialising with friends – can help to take your mind off things and make you feel more in control of your situation.

What are some of your favourite pastimes? Make a list and start planning!

## Finding a 'new normal'

Being diagnosed with melanoma, and undergoing treatment, can be life changing. Once treatment is over, you may feel a sense of relief, but it can often be hard to simply return to 'normal' life.

Perhaps you have a new perspective on life or you're ready for a fresh start. No matter how you feel, it's ok to take time to find your 'new normal'. Here are some tips to help you along:

- **Recognise and accept that life may be different from now on.** There is no need to get 'back to normal' or to start new projects or activities. Do what feels right for you.
- **Think about what is most important in your life.** Do you love spending time with friends and family? Do you like to travel? Build a fulfilling life around what matters most.
- **Join a support group.** Speaking with others in similar situations can help you to feel more supported and optimistic about the future.
- **Channel your energy for good.** Volunteering, fundraising or taking part in a charity event are all great ways to help other people in need.
- **Always talk with your healthcare team** if you have any worries, sadness or low moods.

# Your emotional wellbeing

Everyone deals with the diagnosis and treatment of melanoma differently. It is normal to feel a range of emotions during this time.

From worry and uncertainty about the future, to anger and guilt, these emotions can often be unpleasant or even overwhelming. Regardless of your experience, it is important to acknowledge how you feel, and if possible, talk about your feelings with someone. This is an integral part of looking after yourself.

In the following pages, we will explore some common emotions you may experience and provide some tips on how you can deal with them.



## Worry

Being diagnosed with melanoma can be a frightening experience. It's normal to feel worried or afraid about what the future holds. You may feel worried about:

- treatment, side effects and feeling sick
- the impact of your diagnosis and treatment on your family
- keeping your job during treatment
- managing finances during treatment
- how your relationship with your partner, children, family and friends may change
- whether your family members may be at increased risk of melanoma (read more on page 50)
- what this diagnosis means for your future health.

Uncertainty about the future and feeling like you're not 'in control' of your health or situation is common.

One way you can manage this area of worry is being well-informed and well-prepared for what is to come. It's important to access information from reliable sources. We've listed some good examples on page 56.

Keep a notepad, or use the 'My notes and questions' pages at the end of this guide from page 75, to write down any questions you have for your healthcare team before and between your appointments. Talk with your team to learn as much as you can about your diagnosis and treatment options, so that you are actively involved in your treatment planning.

It can also help to plan how you will manage practical issues during and after your treatment. Think about who you can call on to help with things like cooking, shopping, cleaning and childcare during your treatment and recovery.

## Fear of recurrence or progression

After you have been diagnosed or treated for melanoma, it's very common to worry that the melanoma will come back or spread. This worry is called 'fear of recurrence or progression'.

Fear of recurrence or progression is completely normal, but it can be distressing and unpleasant if not managed. Sometimes, this fear may stop you planning for the future or living your life to the fullest.

**Fear of recurrence or progression is completely normal, but it can be distressing and unpleasant if not managed.**

People generally find this fear does improve over time. However, you may find you worry more at certain times, such as:

- around the time of medical check-ups, examinations or scans (this is also known as 'scanxiety')
- on special occasions like birthdays
- on anniversaries related to your diagnosis or treatment
- when you hear stories about other people who've been diagnosed with cancer
- when you notice a new sign or symptoms, such as skin changes or aches and pains.

If you are finding it difficult to manage your fear of recurrence or progression, or if it's affecting your daily life, it may be time to seek counselling. You can read more about psychological support and counselling on page 53.

### Coping with the fear of recurrence

While nobody can control what the future holds, you can control how much fear of recurrence or progression affects your daily life. Here are a few ways to manage your concerns:

- **Join a support group** – Fear of recurrence or progression is the most common worry experienced by people after treatment for melanoma. It can be a big help to talk to other people who feel or have felt the same.
- **Know your risk for recurrence** – Talk with your healthcare team about your medical history and what that may tell you about the chances of melanoma coming back or progressing.
- **Be aware of symptoms** – It's important to be well informed about the signs and symptoms that may indicate a melanoma recurrence. But also, be mindful that checking your skin too often can be counterproductive! Frequent checking can make it harder to notice small changes in moles over time. It is usually recommended to check your skin monthly, at most. See page 30 for advice on how to conduct a self-examination.
- **Take control of your general health and wellbeing by making healthy choices** – Eat well, exercise regularly, be sun smart and avoid unhealthy habits such as smoking and excessive or frequent drinking.



## Stress

Stress is the way your body reacts to a threatening or harmful situation. Being diagnosed with melanoma might be one of the most stressful things you will ever experience.

Stress can affect both your emotions and your body in very real ways. Some signs that you may be experiencing unhelpful stress include:

- becoming easily agitated
- feeling overwhelmed or out of control
- an inability to focus
- having tense muscles
- experiencing headaches
- having a rapid heartbeat
- trouble sleeping.

While stress is a completely normal reaction to your diagnosis, it can make it harder to cope with everyday life.

Prolonged or chronic stress may impact your everyday life, your ability to engage and enjoy activities and reduce your sense of wellbeing and vitality.

The good news is there are some easy things you can do to lower stress levels.

- **Exercise** – Regular, moderate-intensity exercise can be a big help to relax your body and clear your mind.
- **Mindfulness or meditation** – Practising mindfulness or meditation, even for just a few minutes at a time, can help you to feel calm and at peace. There's no one 'right' way to be mindful or meditate. You could attend a meditation class, download a meditation app on your phone or simply take a few minutes to yourself to sit comfortably and focus your thoughts.
- **Sleep well** – Sleep is an essential element in your recovery. Develop a sleep routine – go to bed at the same time each night and wake up at the same time each day. Avoid stimulants, like caffeine or screen time, within an hour of bedtime.
- **Write a journal** – Writing down the things that are causing you stress, preferably at the time you're aware of it, can be an effective way to release a lot of the tension.

## Loss of identity

Sometimes, being diagnosed with melanoma can change the way you feel about yourself.

There are a number of reasons for this.

- You may find that your treatment and recovery affect the role you play in your family or at work. Changes in everyday arrangements can leave you feeling like you have lost a part of your identity.
- You may feel self-conscious about changes to your body or scars caused by your treatment. This can affect your confidence.
- You may find that you have a new perspective on life. Things that were important to you before your diagnosis may not feel as important now, and vice versa.

There are many ways to manage these feelings. But above all, it's important to allow yourself time to adjust. You have experienced a life-changing event. Be kind to yourself and take time to get to know the 'new you'!

Other ways to cope with a loss of your old identity include:

- **Join a support group** – Talking to other people who are feeling the same as you, to better understand your own experience and give you hope for the future.
- **Talk openly about your feelings** – Talk with your family and friends about how you are feeling. It can be hard for them to understand what you are experiencing. But letting them know how you feel can help them to support you.
- **Keep active** – Regular exercise can clear your mind and help you to feel in control of your body.
- **Seek psychological support** – If your feelings are continuing to cause you serious worry or concern, speak with your healthcare team about accessing a psychologist or counsellor. You can read more about psychological support and counselling on page 53.

## Anger

Being diagnosed with melanoma might make you angry. It's an inconvenient disruption to your life plans and it's not uncommon to think, 'Why has this happened to me?'

Some people may feel anger over the way they were diagnosed. Perhaps you were misdiagnosed initially or experienced delays in diagnosis.

Feeling anger and hostility is unpleasant – it can make you physically tense and tired. So it's best to take some steps to not let anger build up.

It can help to talk through your feelings with someone you trust or channel your energy into a physical activity, like jogging or boxing.

## Guilt

It's common for people with melanoma to experience feelings of guilt for various reasons. For example, you may feel guilty because:

- you blame yourself for past sun exposure that may have increased your risk of melanoma
- you could have noticed signs or symptoms, or acted on them, sooner
- you worry that you might be a burden to your family and carers
- you worry about not being able to fulfil your normal role in your family
- you worry about the financial strain that your treatment may cause

- you are concerned that you may have passed a specific faulty gene that causes an increased risk of melanoma to your children.

It's important to remember that melanoma is not your fault. Letting go of guilt, by sharing your feelings or joining a support group, is important for improving your emotional wellbeing.

**Letting go of guilt, by sharing your feelings or joining a support group, is important for improving your emotional wellbeing.**

### Genetics and melanoma

Melanomas themselves are not passed on from person to person but our risk of melanoma certainly is hereditary - it is affected by our genetic background. Rarely, a specific faulty gene that carries melanoma risk may be passed from one generation to the next. But for most people it is the combination of a lot of genetic differences that pushes our risk up or down: such as our different skin colours, the way we react to the sun, the number of moles, and other invisible effects of our genetic makeup.

## Anxiety and depression

A melanoma diagnosis can have a huge impact on your life. It's normal to feel worried, stressed, sad and scared during this time.

Sometimes, these feelings are overwhelming and start to interfere with your daily life. If this sounds like you, you may be experiencing clinical anxiety or depression.

People diagnosed with melanoma are at higher risk of developing anxiety or depression and may require psychological support and treatment.

## Know the warning signs

### Signs of clinical anxiety

- Feeling agitated or on edge
- Trouble focusing and problem solving
- Trouble sleeping
- A need for constant reassurance
- Muscle tension, trembling or shaking
- Increased heart and breathing rate
- Sweaty palms
- Knots in the stomach
- Racing thoughts

### Signs of clinical depression

- Feeling low, hopeless or flat for most of the day
- Losing pleasure or interest in things you used to enjoy
- Trouble sleeping, or sleeping too much
- A loss of appetite
- Difficulty concentrating
- Feeling an excessive amount of guilt
- Frequent thoughts of death or suicide

Talk to your healthcare team if you think you may have anxiety or depression. You are not alone.

There are programs, support groups and helplines that may be useful for you. You can read more about accessing psychological support on page 53.

Professionals such as psychologists or counsellors can provide you with strategies to help you cope with your situation.

### **Emotions and Cancer**

Booklet available from Cancer Council



[cancercouncil.com.au](http://cancercouncil.com.au)  
13 11 20

### **Living Well After Cancer**

Booklet available from Cancer Council



[cancercouncil.com.au](http://cancercouncil.com.au)  
13 11 20

# Getting help and support

Everyone's experience with melanoma is different, and so are their supportive care needs. In this section, we explore a number of support services available to you.

## Help from a psychologist or counsellor

Just like your GP, dermatologist, surgeon or nurse have helped to treat the physical symptoms of melanoma, a psychologist or counsellor can help you to manage your emotional health.

A **psychologist** is an expert in emotions, behaviour and thoughts. They can diagnose mental health illnesses and offer evidence-based strategies to help manage these issues. Psychologists are members of a regulated profession and require a formal registration to practise. However, they cannot prescribe medication.

A **counsellor** is someone who can listen to your issues and concerns and offer you strategies to deal with them. A counsellor does not require any formal qualifications to practise, although many counsellors do have recognised training.

If you are feeling anxious or depressed – or experiencing any other emotions that are having a negative impact on

your daily life or wellbeing – you may need to seek help from a psychologist or counsellor.

Someone in the healthcare team managing your melanoma treatment can put you in touch with a psychologist or counsellor who can provide tailored support for you. Alternatively, your GP can also help with directing you to one of these providers and may be able to advise you on eligibility for Medicare rebates for some of these services.

You can also:

- visit [psychology.org.au](https://psychology.org.au) to search for a psychologist in your area. The 'Find a psychologist' search function on the website allows users to search for a psychologist working in cancer support
- call the Cancer Council on **13 11 20** to find a psychologist specialising in cancer support in your area.

**If you need immediate crisis support, call Lifeline on 13 11 14.**

## Help from a support group

While it is really helpful to have a network of family, friends and carers to lean on for support, sometimes you may prefer to speak about your experience with people in a similar situation. Face-to-face or online support groups can be a powerful way to share stories and information and learn from the experience of others.

Support groups are available for people with melanoma, their family and friends. Access to face-to-face support groups will differ depending on where you live.

### Melanoma Institute Australia

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

(02) 9911 7200

Melanoma Institute Australia support groups are run monthly in collaboration with Melanoma Patients Australia. Visit the website to find details on a group near you.

### Melanoma Patients Australia

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

1300 884 450

Melanoma Patients Australia (MPA) provides a range of support options throughout Australia, including:

- one-on-one telephone support where you can speak with a person who understands your experience and can provide you with helpful information

- peer-to-peer linkages where you can speak with another person who has had a similar experience to you
- face-to-face support groups in a number of locations
- a private Facebook support group: Melanoma Patients Australia Closed Support Group
- a telephone support group.

To access any of these support services, contact the MPA Support Line on 1300 884 450.

### Skin Cancer Tasmania

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

0409 330 206

Skin Cancer Tasmania offers one-on-one and group support sessions in Tasmania.

Email [info@skincancertas.org.au](mailto:info@skincancertas.org.au) for more information.

### MelanomaWA

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

(08) 9322 1908

MelanomaWA hold monthly meetings throughout Western Australia, and also offer one-on-one and peer-to-peer support.

Email [wa@melanoma.org.au](mailto:wa@melanoma.org.au) for more information.

## Cancer Council

Cancer Councils throughout Australia offer a number of online and telephone support options.

### **Cancer Council Online Community** [onlinecommunity.cancer council.com.au](https://onlinecommunity.cancer council.com.au)

This Cancer Council service is a moderated online community where you can ask questions and participate in groups, forums and blogs.

### **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 Connect**

02 9334 1870 or 13 11 20

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.

## Melanoma Nurse Telehealth Service

A specialist melanoma nurse service is available to support patients in navigating the health system, accessing available services and making decisions regarding their health. This personalised telephone support service from Melanoma Patients Australia and supported by Melanoma Institute Australia is available to all melanoma patients and their carers.

Phone 1300 884 450 to book an appointment or visit [melanomapatients.org.au](https://melanomapatients.org.au) to find out more.

## Psychologists

**Australian Psychological Society**  
[psychology.org.au](https://psychology.org.au)

1800 333 497

## Lymphoedema

**Australasian Lymphology Association**  
[lymphoedema.org.au](https://lymphoedema.org.au)

1300 935 332

## Exercise

**Exercise and Sport Science Australia**  
[essa.org.au](https://essa.org.au)

07 3171 3335

## Nutrition

### Dietitians Australia

[daa.asn.au](http://daa.asn.au)

1800 812 942

## Finding information online

While the internet can be a helpful source of information it can also be overwhelming and inaccurate. Not all medical information available online is evidence-based – and it can be hard to tell the difference between fact and fiction.

To help, we've listed some useful websites that provide reliable melanoma information. But always remember to discuss any information from the internet with your healthcare team as they will be able to discuss it with you in terms of your individual circumstances.

### General Australian websites:

#### Melanoma Institute Australia

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

#### Melanoma Patients Australia

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

#### Cancer Council Australia

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

#### Myths about cancer

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

#### eviQ Patient and Carers

[eviq.org.au/patients-and-carers](http://eviq.org.au/patients-and-carers)

## International websites

### Macmillan Cancer Support

[macmillan.org.uk](http://macmillan.org.uk)

### US National Cancer Institute

[cancer.gov](http://cancer.gov)

### American Cancer Society

[cancer.org](http://cancer.org)

### MD Anderson Cancer Center

[mdanderson.org](http://mdanderson.org)

## Reliable written resources

### Understanding Melanoma

This Cancer Council booklet is available online or you can order a copy by phoning the number below.

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

13 11 20

### A guide to understanding melanoma: A starting point for people in their journey with melanoma

Melanoma Patients Australia has made this booklet available online or you can contact them for a copy to be sent to you.

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

1300 884 450

# Your family and friends

Your diagnosis of melanoma can be overwhelming for your friends and family as well. They might not know what to say to you, or they may feel sad or worried for you.

In this section we'll explore how to talk about your diagnosis with your family and friends and how they can best support you during and after treatment.

## Talking to your family and friends about your diagnosis

It's totally up to you how much or how little you want to share with them. When you feel ready to talk, the following tips may help you to have that conversation.

- Choose a quiet place and a time when you will not be interrupted.
- Be clear about your diagnosis. It is not helpful to avoid words like 'melanoma' or 'cancer'.
- Tell them slowly, using short and clear sentences. Give them time to take in what you are saying.

- Check they understand and do your best to answer any questions they may have.
- Understand that they may get upset and you may need to comfort them – even though you are the one with melanoma.
- Allow time for silence and thought.

Telling your loved ones that you have melanoma can be difficult. But it's an important first step in helping them to help you.

## Talking to young children about your diagnosis

Parents and carers can find it challenging to talk about a melanoma diagnosis with their children, grandchildren or other young children in their life.

Most children will sense that something is happening. It's important to discuss your diagnosis with them so that they are not left to imagine the worst.

## Helpful resources:

### Talking to Kids About Cancer

Cancer Council has produced a comprehensive guide for talking to young children about your diagnosis. It outlines how to have this discussion in age appropriate ways.

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

13 11 20

### CanTeen

Information for young people between the ages of 12–25

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

1800 835 932

## Ways your family and friends can help

You may find that your family and friends are keen to help you during and after your melanoma treatment. Sometimes it can be difficult to accept help from others – maybe you feel like you can handle it, or you want to maintain your privacy. But at some point, you may be very grateful for the offer. This extra help can make all the difference.

Try to be specific about the type of help you want or need when a friend or family member says, “What can I do to help?”. And remember, there will be times when you’re not sure what help you need. That’s ok. Allow your family and friends to offer something they can do for you.

Your family and friends can help by:

- attending medical appointments with you to take notes so that important information is not missed
- driving you to appointments, the shops or anywhere you need to go
- cooking meals for you and your family
- helping to look after your children.
- distracting you with enjoyable activities
- simply being around!



## Information and support for carers

Carers play a vital and demanding role. It's common for carers to experience a range of emotions about their role – from worry about your loved one to frustration or stress about your situation.

If you are caring for someone with melanoma, it's important to look after yourself as well so that you're able to provide the best level of support you can.

Take time away from your caring duties to rest. The person you are caring for may also appreciate some time alone.

## Information and support resources

### Caring for someone with cancer

Booklet available from Cancer Council

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

13 11 20

### Cancer Council Telephone support group for carers

Cancer Council provides fortnightly phone groups:

- for people who are providing primary care for a family member, friend or loved one with a cancer diagnosis.

To register, call 13 11 20, 1300 755 632 or email [tsg@nswcc.org.au](mailto:tsg@nswcc.org.au).

### Carers Australia

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

1800 242 636

Access carer information, advisory and counselling services.

### Young Carers Network

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

1800 242 636

Access information, support and financial aid services.



# Your melanoma organiser

# 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 .....

## Result

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.

Stage of melanoma .....

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

## My pathology report

(Ask your doctor to help you complete this page)

Patient name:

DOB/Sex:

Requested by:

Requested on:

Specimen received:

### PATHOLOGY REPORT

#### CLINICAL DETAILS

#### MACROSCOPIC

#### MICROSCOPIC REPORT

Specimen type:

Site:

Diagnosis:

Classification/Main pattern:

Thickness:

Clark level:

Ulceration:

Dermal mitoses:

Margins of excision:

- Invasive component to nearest peripheral margin:
- Insitu component to nearest peripheral margin:

#### SUMMARY

# My treatment summary

## 1.

Date of wide excision .....

Doctor performing the wide excision .....

Flap or skin graft needed  Yes  No

Sentinel node biopsy needed  Yes  No

Sentinel node biopsy result  Positive (Melanoma)  
 Negative (No melanoma)

Clear excision margins  Yes  No

## 2.

### Further surgery

Date of surgery .....

Reason for procedure .....

Doctor performing procedure .....

## 3.

### Adjuvant (additional) treatment

Date of treatment .....

Type of treatment .....

Reason for treatment .....

Doctor providing treatment .....

4.

**Wound care**

Suture removal or dressing change .....

Post surgical appointment .....

5.

**Side effects experienced**

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

# My follow-up plan

My follow-up appointments will be with Doctor .....

My appointments will be (please tick)  3  4  6  12 monthly

Tests or scans prior to follow-up appointment .....

.....  
.....

I will check my own skin every  months

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

.....  
.....

## My notes or questions

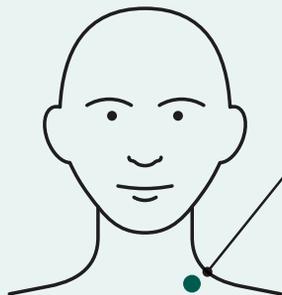
.....  
.....  
.....  
.....  
.....

See pages 30–31 for more about skin examination and follow-up.

## Body map

Use the body map on the next page to mark any moles or 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



12/12/2020 – new, 2 mm, brown

20/12/2020 – checked by doctor

31/01/2021 – no change

28/03/2021 – changed: 3 mm,  
red spots, needs checking by doctor

Use this 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

3 mm



5 mm



7 mm



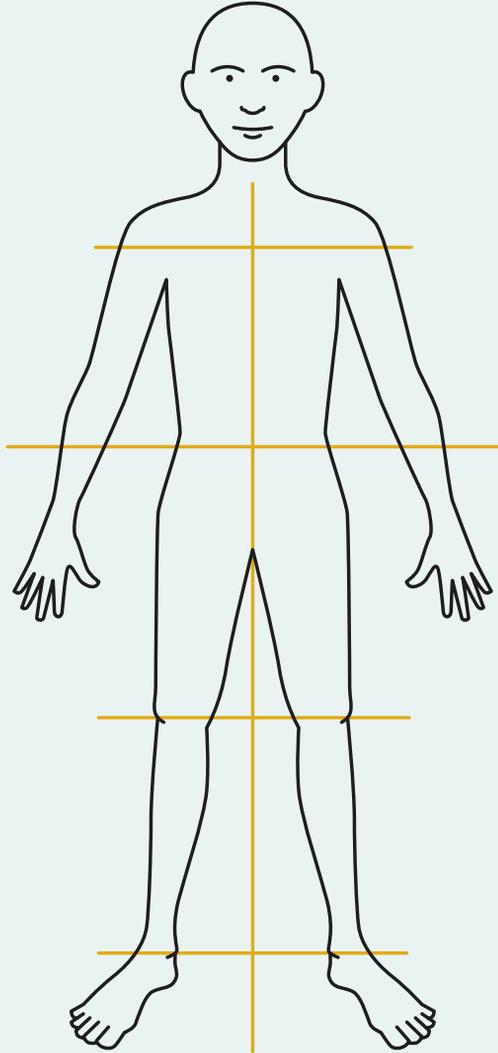
9 mm

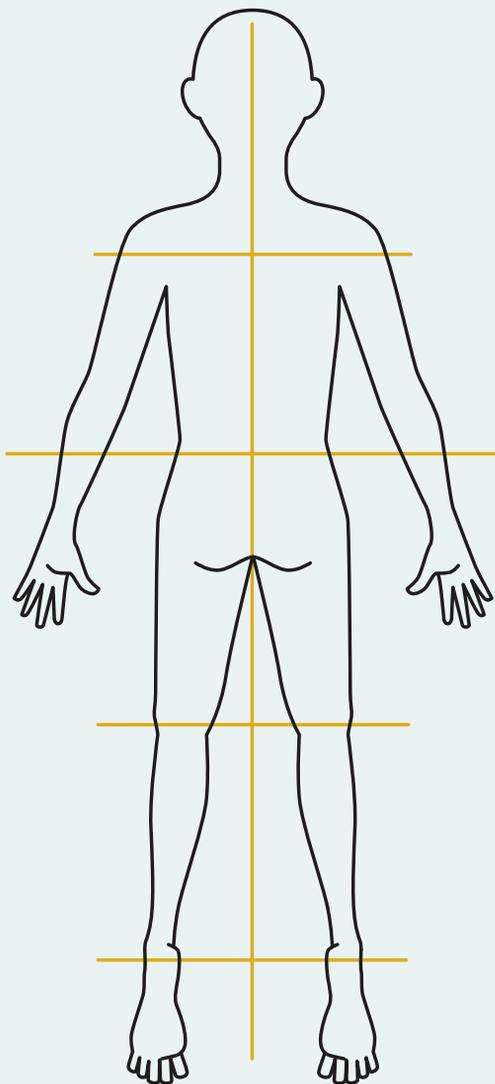


11 mm



### Body Map





# My healthcare team

You may have several different health professionals. Use this space to record contact details for people involved in your care or those able to provide you with advice and support.

## Health professionals you may see

### General Practitioner

A doctor who manages your screening, diagnosis, general health needs and follow-up care.

### Surgeon

A doctor who operates to remove the melanoma. You may see a general surgeon or a plastic surgeon.

### Dermatologist

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

### Nurse

A nurse may educate and support you with wound care, assist to co-ordinate and manage your care and manage symptoms in the community.

## My healthcare team

Name .....

Occupation/Department .....

Phone .....

Email .....

Address .....

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

Notes .....

Name .....

Occupation/Department .....

Phone .....

Email .....

Address .....

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

Notes .....

Name .....

Occupation/Department .....

Phone .....

Email .....

Address .....

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

Notes .....

Name .....

Occupation/Department .....

Phone .....

Email .....

Address .....

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

Notes .....

Name .....

Occupation/Department .....

Phone .....

Email .....

Address .....

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

Notes .....

Name .....

Occupation/Department .....

Phone .....

Email .....

Address .....

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

Notes .....

# My appointments

Appointment with .....

On ..... / ..... / ..... At ..... am/pm

Location .....

Reason for appointment .....

Notes:.....

.....

Appointment with .....

On ..... / ..... / ..... At ..... am/pm

Location .....

Reason for appointment .....

Notes:.....

.....

Appointment with .....

On ..... / ..... / ..... At ..... am/pm

Location .....

Reason for appointment .....

Notes:.....

.....

Appointment with .....

On ..... / ..... / ..... At ..... am/pm

Location .....

Reason for appointment .....

Notes:.....  
.....

Appointment with .....

On ..... / ..... / ..... At ..... am/pm

Location .....

Reason for appointment .....

Notes:.....  
.....

Appointment with .....

On ..... / ..... / ..... At ..... am/pm

Location .....

Reason for appointment .....

Notes:.....  
.....





A series of horizontal dotted lines for writing notes.



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. systemic therapy following surgery).

## Atypical moles

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

## Benign

Not cancerous.

## 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).

## Naevus

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

A technique to see if the melanoma has spread to the lymph nodes closest to the original primary melanoma site. This is an excellent indicator of the prognosis of a patient's melanoma.

## 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.

# Acknowledgements

This guide was conceived by Associate Professor Robyn Saw and created with the assistance and support of many health professionals, staff and patients of Melanoma Institute Australia.

The generosity of those diagnosed with melanoma and their families who shared stories, and gave their time and energy to this project, is very much appreciated.

## **Disclaimer**

Melanoma Institute Australia does not accept any liability for any injury, loss or damage incurred by the use of or reliance on the information. Melanoma Institute Australia develops material based on the best available evidence, however it cannot guarantee and assumes no legal liability or responsibility for the currency or completeness of information. This guide is protected by copyright and should not be duplicated without the authors' permission. While the information contained in this guide has been presented with all due care, changes in circumstances after the time of the publication may impact on the accuracy of the information. Links to internet sites and other organisations are provided for information only. Care has been taken in providing these links as suitable reference resources. However, due to the changing nature of the internet, it is the responsibility of users to make their own decisions and enquiries about the information retrieved from internet sites or other organisations.





The Poche Centre  
40 Rocklands Road  
Wollstonecraft NSW 2065  
Australia  
P 02 9911 7200  
F 02 9954 9290  
E [info@melanoma.org.au](mailto:info@melanoma.org.au)

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

