

Your Guide

to Stage III Melanoma

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

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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 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.

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 book 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 book 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 Stage III melanoma or would like more information about melanoma, then this guide is for you.

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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](https://www.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

Medical Director

Melanoma Institute Australia

Joint 2024 Australian of the Year



About melanoma

What is melanoma?

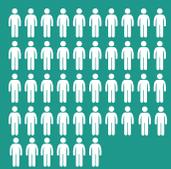
Melanoma is a form of cancer that develops in the body's pigment cells, known as melanocytes. Melanoma occurs when abnormal melanocytes grow in an uncontrolled way and evade the immune system.

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.

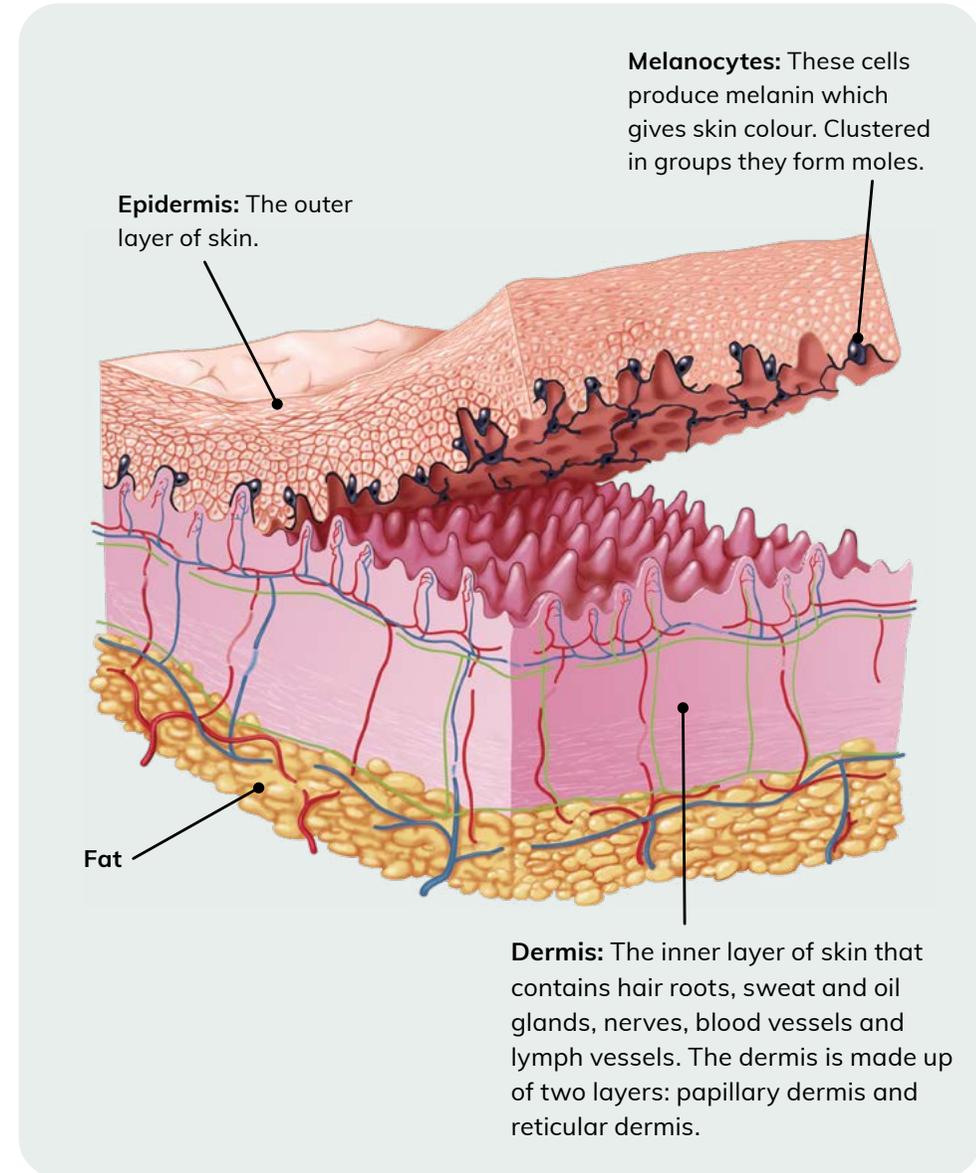
A primary melanoma is the site of origin of a melanoma.

Australia has the highest rate of melanoma in the world.



On average, **46 Australians will be diagnosed with melanoma every day; that is close to one diagnosis every half hour.**

The skin

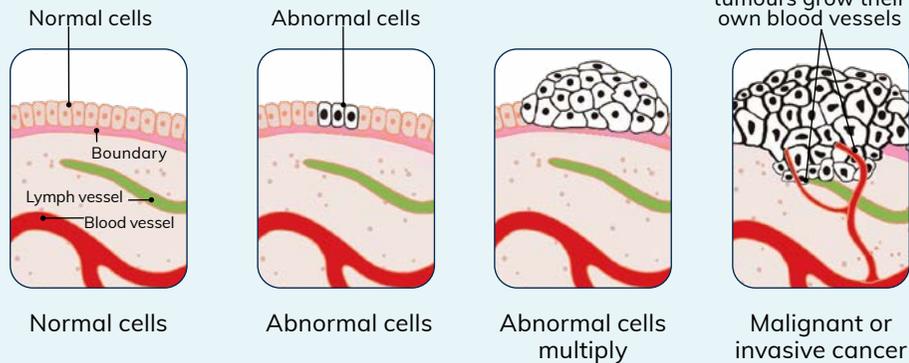


How cancer grows and spreads

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.

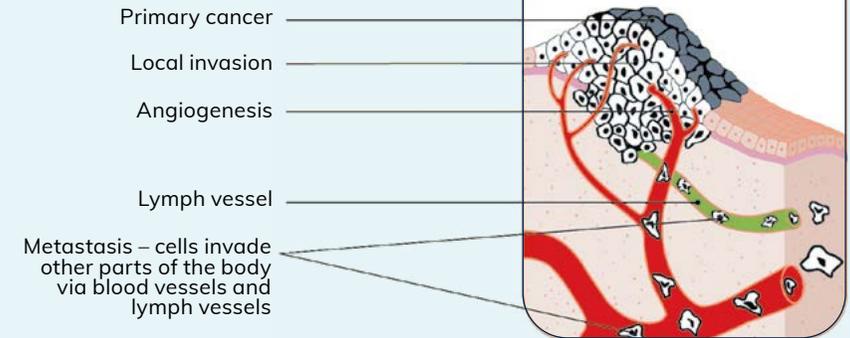
Cancer occurs when abnormal cells grow and divide in an uncontrolled manner, forming a tumour.

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 systems. This process is called metastasis.

How cancer spreads



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 23–38.

Diagnosis and staging of 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.

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. Lymph node spread may be detected when it is microscopic (too small to be seen or felt) or when it is palpable (felt as a lump under the skin).

Microscopic spread is detected using a procedure called a sentinel node biopsy. Microscopic spread generally has a better prognosis than spread that can be seen or felt by a doctor.

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.

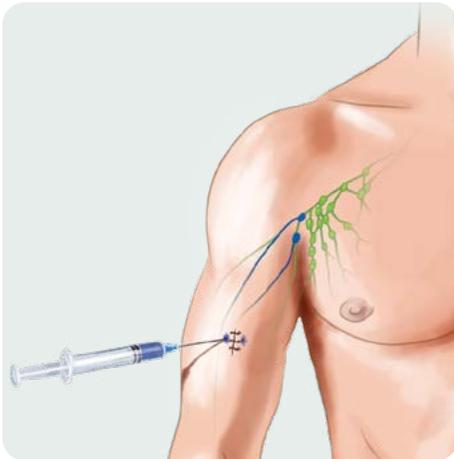
The sentinel node is the first lymph node or nodes that filter lymphatic fluid from the area of skin that has melanoma. If the cancer has spread, the sentinel node is the most likely node to have cancer in it.

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 see a surgeon to discuss further treatment which may include regular

ultrasound to determine if other lymph nodes are involved or a complete lymph node dissection, where all lymph nodes in the affected area are removed. You can read more about lymph node dissection on page 27.

You may also be referred for discussion about systemic therapy. You can read more about systemic therapy on page 31.



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.

Read more about
sentinel node biopsy
at melanoma.org.au



Palpable lymph nodes

If you present with an enlarged lymph node which is felt as a lump under the skin or found on an ultrasound scan, your doctor will usually organise a fine needle biopsy.

Fine needle biopsy

A fine needle biopsy or core biopsy examines cells inside a 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, and potentially also a medical oncologist to discuss drug therapy in addition to surgery.

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 appear as visible deposits in the skin, or underlying soft tissue, around the primary site. When the cells appear within 2cm of the primary site, it is called satellite disease, or satellite metastases. When the cells appear further than 2cm from the primary site, it is called in-transit disease, or in-transit metastases.

Microsatellite metastases are similar to satellite metastases but can only be detected by microscopic examination.

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 and possibly a medical oncologist to discuss further treatment.

Pathology results

Following a 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.

Lymph node pathology report

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). The greater the number of lymph nodes containing melanoma, the poorer the prognosis. Extra-nodal spread is also associated with a poorer prognosis.

Sample primary melanoma pathology report

Patient name: FULLER, Joshua
DOB/Sex: 22/04/1962, M
Requested by: Dr Sattler, Jeanette
Requested on: 11/01/2026
Specimen received: 12/01/2026

PATHOLOGY REPORT

CLINICAL DETAILS

Palpable mass in right axilla.

MACROSCOPIC

A piece of fatty tissue measuring 155 x 75mm and up to 15mm in thickness. A firm nodule with a brown/black cut surface measures 30 x 25 x 15mm.

MICROSCOPIC REPORT

Type of surgery: Right axillary lymph node dissection
 Diagnosis: Metastatic melanoma
 Total number of nodes found: 12
 Total number of positive nodes: 1
 Size of the largest tumour deposit: 30mm
 Extranodal spread: Present
 Margins of resection: Clear, 4mm
 Extranodal deposits: Not present

SUMMARY

Right axillary lymph node dissection, METASTATIC MELANOMA

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.

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.

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.

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 mm² and can indicate how quickly the melanoma cells are growing. Higher mitotic rates (e.g. greater than 5 per mm²) 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.

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. This 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"> – Surgical removal (wide local excision)
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"> – Surgical removal (wide local excision) – Sentinel node biopsy may be considered to rule out spread of melanoma to lymph nodes
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"> – Surgical removal (wide local excision) – Sentinel node biopsy may be considered to rule out spread of melanoma to lymph nodes – Consideration of additional drug (systemic) therapy treatment after surgery
Stage III	Melanoma has spread to local lymph nodes or nearby tissues (in-transit disease).	<ul style="list-style-type: none"> – Assessment for additional treatment before (neoadjuvant) or after surgery (adjuvant), such as with drug (systemic) therapy – Surgical removal (local excision) for in-transit disease – Consideration of lymph node dissection (removal of all lymph nodes in the affected region)
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"> – Drug therapy may be used – Radiation therapy or surgery may also be considered

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. The subgroups of Stage III are defined by the characteristics of the original melanoma (such as its depth and whether it was ulcerated), the draining lymph node and whether the disease has spread to surrounding tissues. The characteristics of each subgroup have been summarised in the table below. Staging a melanoma can be confusing! Your healthcare team can talk you through how this applies to your situation.

Stage	Characteristics
IIIA	<ul style="list-style-type: none"> – The cancer is no more than 2mm thick. It may or may not be ulcerated. <p>AND</p> <ul style="list-style-type: none"> – 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.
IIIB	<ul style="list-style-type: none"> – There may be no sign of the primary melanoma. However, melanoma cells have spread to 1 lymph node that can be felt OR to very small areas of nearby skin or lymphatic vessels. <p>OR</p> <ul style="list-style-type: none"> – The melanoma is up to 4mm thick. It may or may not be ulcerated. Melanoma cells have spread to up to 3 lymph nodes (some of these may be seen or felt, or they may be detected by biopsy) OR to very small areas of nearby skin or lymphatic vessels.

Stage	Characteristics
IIIC	<ul style="list-style-type: none"> – There may be no sign of the primary melanoma. However, melanoma cells have spread to 2 or more nearby lymph nodes, at least one of which can be seen or felt OR to lymph nodes that are clumped together OR to very small areas of nearby skin or lymphatic vessels, and it has reached nearby lymph nodes. <p>OR</p> <ul style="list-style-type: none"> – The melanoma is up to 4mm thick. It may or may not be 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, and it has reached nearby lymph nodes. <p>OR</p> <ul style="list-style-type: none"> – The melanoma is between 2.1 and 4mm thick and is ulcerated, or thicker than 4mm but not ulcerated. Melanoma cells have spread to 1 or more lymph nodes AND/OR to very small areas of nearby skin or lymphatic vessels. <p>OR</p> <ul style="list-style-type: none"> – The melanoma is thicker than 4mm and is ulcerated. Melanoma cells have spread to more between 1 and 3 lymph nodes, which are not clumped together OR to very small areas of nearby skin or lymphatic vessels, and it might or might not have reached 1 nearby lymph node..
IIID	<ul style="list-style-type: none"> – 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, and has reached at least nearby 2 lymph nodes or lymph nodes that are clumped together.

This information is based on the 8th edition of the American Joint Committee on Cancer Staging Manual, implemented from January 2018.

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 64.

'Prognosis' is a term used to describe the likely outcome of a medical condition. If you would like to know more about the prognosis for your specific circumstances, speak with a member of your treatment team.

Support for you



Questions you may like 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 provides a subsidy for 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
- Systemic therapy (treatment with drugs)
- Radiation therapy.

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.

Melanoma guide to best cancer care

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

cancer.org.au/cancercareguides/melanoma



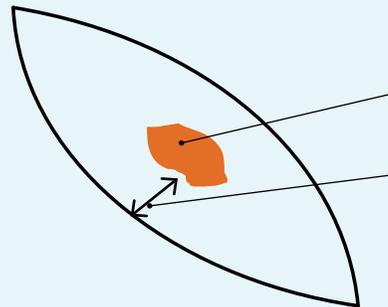
Surgery

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 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.



This is the melanoma which needs to be removed.

This is the margin - an area of healthy skin around the melanoma that is taken to check that all cancer cells are removed. The width of the margin depends on the thickness of the melanoma.

Lymph node dissection

Following a positive sentinel node biopsy

In the past, when melanoma had spread to nearby lymph nodes, a surgery called a lymph node dissection was typically required. This involved the removal of all the lymph nodes in the affected area.

Results from recent clinical trials tell us that a lymph node dissection is not always the best option for people with a positive sentinel node melanoma.

If you had a positive sentinel node biopsy, your healthcare team will discuss the best treatment approach for you.

Lymph node dissection

Lymph node dissection may be performed in selected cases. This may happen 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 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 may 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 lymph node dissection and exercises, and lymphoedema. Visit melanoma.org.au to find out more.



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 now usually recommended before and sometimes after surgery to reduce the chance of the melanoma recurring (coming back). Systemic therapy given before surgery is called '**neoadjuvant**' while therapy given after surgery is referred to as '**adjuvant**'.

Currently, there are two main types of systemic therapy used to treat melanoma: immunotherapy and targeted therapy. Targeted therapy is used less commonly as neoadjuvant therapy.

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 reduce the risk of melanoma recurrence, regardless of your genetic mutation test result.

One type of immunotherapy currently available to treat Stage III melanoma are checkpoint inhibitors. These drugs block proteins on the surface of immune 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. Nivolumab and pembrolizumab are checkpoint inhibitors that are approved for treatment after resection of Stage III melanoma.

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.

Understanding Immunotherapy

Resource available from Cancer Council: cancercouncil.com.au



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:

- rash
- fatigue.

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.

What is neoadjuvant immunotherapy?

'Neoadjuvant therapy' refers to any treatment given before the main treatment (which is usually surgery) for a cancer. Immunotherapy is a type of cancer treatment that works by helping the body's own immune system recognise and attack cancer cells more effectively.

When immunotherapy is given before surgery, it is called 'neoadjuvant immunotherapy'.

For many patients, treating the melanoma with immunotherapy first can shrink the tumour which sometimes make surgery less extensive, and it significantly reduces the risk of the cancer returning.

Many side effects will go away when treatment ends, but some side effects can also occur after stopping treatment. Side effects affecting hormone production (e.g. the thyroid) may be permanent.

Be sure to speak to your healthcare team if you're experiencing side effects that you need help managing. If you receive treatment at an Emergency Department, be sure to inform the doctors that you are receiving immunotherapy and, if possible, provide the name of the drug/s you're taking and the name of your Medical Oncologist.

It also provides doctors with personalised information about how the tumour is responding, which can help guide decisions about treatment after surgery.

Although it is natural to be concerned about delaying surgery, receiving immunotherapy first does not put you at a greater risk - in fact, it can lead to a better overall survival. Your treatment team will carefully monitor your progress throughout treatment and will adjust your plan promptly if the melanoma is not responding as expected. To find out more, visit melanoma.org.au and download our Patient Information Brochure 'Neoadjuvant immunotherapy for melanoma.'

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 a key genetic mutation that drives the growth of melanoma in approximately 40% of patients. It is known as BRAF ('BEE-raff').

Other target genetic mutations currently being investigated are:

- NRAS ('EN-rass')
- C-KIT ('SEE-kit').

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 is a targeted therapy

combination that is available on the PBS for patients with resected Stage III melanoma with a BRAF-mutation.

This regimen combines a drug that targets the 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 combination is a BRAF inhibitor called dabrafenib and a MEK inhibitor called trametinib.

There are currently no therapies available specifically to treat NRAS-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.

eviQ

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



Take a look at our Patient Information Brochures at melanoma.org.au to find out more:

- Your diet, your gut and immunotherapy
- Neoadjuvant immunotherapy for melanoma

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.

Side effects of BRAF/MEK targeted therapy

The most common side effect seen with this targeted therapy combination is fever.

Other side effects may include:

- skin problems (rash, dry skin)
- diarrhoea or constipation
- liver problems, such as hepatitis or elevated liver enzymes
- rarely, heart or eye problems.

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. Most side effects of targeted therapy go away after treatment ends.

Radiation therapy

Radiation therapy uses x-rays to target and kill cancer cells by damaging their DNA. As newer and more effective systemic therapies become available, radiation therapy is less commonly used in the treatment of Stage III melanoma.

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 comes from a machine outside your body.

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

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.

Treatment options considered for Stage IV melanoma, such as systemic therapies and radiation therapy, may be a suitable treatment for unresectable melanoma. You can read more about treatment options for Stage IV melanoma in *Your Guide to Stage IV Melanoma* available from Melanoma Institute Australia.

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. For example, trials may look at the benefits and outcomes of using drug treatments prior to surgery.

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. Search for current clinical trials at the Melanoma Institute Australia website (melanoma.org.au).

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

Understanding Clinical Trials and Research

For more information on clinical trials and research studies, visit: melanoma.org.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.



A patient undergoing total body photography. These photographs are stored and used as a reference point in future examinations to help detect skin changes over time.

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.

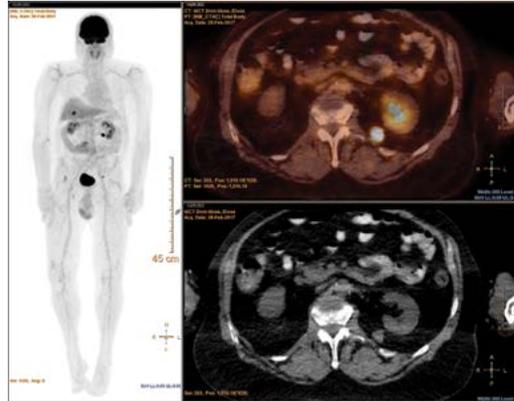
Imaging scans use different methods to create an image of your insides. You may need to prepare for these scans by fasting (no food or drink), and you may be given an intravenous injection before the scan to help produce an informative image of what is going on.

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, the spinal cord and liver.

- **PET (positron emission tomography)** uses glucose tagged with radiotracers to observe how active cells are in the body. PET and CT scans will be combined to give a more complete picture.

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.



PET scan showing liver metastases.

Self examination

Being familiar with your skin will allow you to recognise changes early and act quickly.

What to look for

The first sign of a melanoma is usually the appearance of a new spot, or a change in an existing freckle or mole. The change is normally noticed over several weeks or months.

Here is a simple ABCDE guide to monitor your skin for early signs of melanoma. Seek medical advice if you see any of the following changes to a mole:

A Asymmetry

One half does not match the other.



B Border irregularity

The edges are irregular, ragged, notched or blurred.



C Colour variation

The colour is not the same all over, but may have shades of brown or black, or even red, white or blue.



D Diameter

The area is larger than 6mm, or is growing larger.



E Evolution

Changing in size, shape, colour, elevation or another trait (such as itching, bleeding or crusting). This last point is likely the strongest of all the warning signs.



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.

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 speak with your doctor about your risk and how often you should have a professional skin check.

Body maps

If you have moles or lesions you want to keep an eye on simply draw them on the body maps on pages 88 and 89 along with the date and any comments.



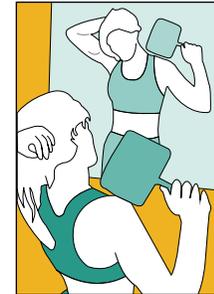
Photographing your moles

Several smartphone apps allow you to photograph your skin and set reminders for skin checks. They can be really helpful for keeping track of your moles over time, making it easier to detect changes. However, they cannot reliably diagnose skin cancer and should not replace a visit to the doctor. If you find something you are worried about, make sure you see your doctor.

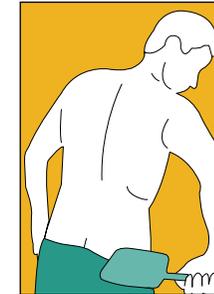
Where to look

Make sure you check your entire body, including skin that is not normally exposed to the sun. Don't forget to check around your excision site, including your lymph nodes in that area for any new lumps.

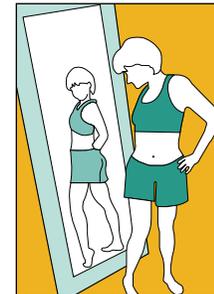
If you have many moles, your doctor may recommend body photography to assist in monitoring the skin.



Head, scalp, neck and ears. Use a hand-held mirror to examine your face, scalp and neck areas. Ask someone to check areas you can't see easily.



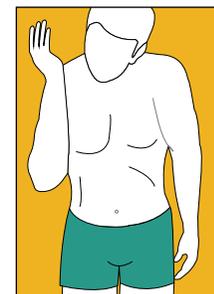
Buttocks and legs. Check all sides of your legs from ankles to thighs.



Torso. While standing in front of a mirror, check the front and back of your torso, then the right and left sides with your arms raised.



Feet, including soles and toes. Take a seat and check the soles of your feet, between your toes and your toenails.



Arms, hands, fingers and nails. Bend your elbows and look carefully at forearms and upper arms. Check your palms, fingernails and between your fingers.

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.

Take a look at our Patient Information Brochure at melanoma.org.au called "Genetics and your risk of melanoma" to find out more.



The Centre for Genetics Education has some information and a factsheet.

genetics.edu.au

Search for 'Factsheet 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 all five sun safe rules:



Seek shade



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

To protect yourself fully, it is important that you utilise all of these sun safe measures throughout the day, rather than just relying on one.

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 eye wear that offer good sun glare and UV protection.

Keep an eye on the UV index in your area by downloading the **SunSmart Global UV 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.

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.

Using sensible sun protection when outdoors does not put you at risk of developing vitamin D deficiency.

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.



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?

Self-care and support

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

Keep up to date with your scheduled follow-up visits and monitor your general health. Record details of your follow-up plan and appointments in Your Melanoma Organiser at the end of this Guide, from page 73.

Keeping active

Being physically active and exercising regularly is important for your physical health, your emotional wellbeing and your quality of life. For those undergoing systemic therapy or radiotherapy, exercise has been shown to ease side effects, including fatigue.

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.

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 healthcare 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.

If you're receiving immunotherapy, having a healthy diet may also help to enhance the way your treatment works. There is increasing evidence of a link between our immune systems and the microorganisms in our gut. Studies have shown that a healthy diet can impact our gut microorganisms and thereby improve the activity of immunotherapy. There is also increasing evidence that a healthy diet can reduce the side effects of immunotherapy.

Choose fresh vegetables, fruit, nuts, lean meat, fish and non-processed foods. Try to drink 6 to 8 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 dietitiansaustralia.org.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 during and after your treatment for melanoma, especially if your treatment involved extensive surgery.

If you are receiving systemic therapy or radiotherapy, be realistic about how much you can do immediately following a treatment cycle. You may have good days and bad days.

No matter what your treatment involves, don't push yourself to do too much, 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.

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.

Nutrition and Cancer

Resource available
from Cancer Council
cancercouncil.com.au
13 11 20



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 overwhelming. Regardless of your experience, it is important to acknowledge and express how you feel and look after yourself accordingly.

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

Finding out that you have melanoma that has spread to lymph nodes or nearby parts of the body 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 unknown aspects of participating in a clinical trial or starting a new therapy that not much is known about
- further disease progression and what this diagnosis means for your future health
- 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 are now at increased risk of melanoma (read more on page 61).

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

One way you can manage 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 67.

Write down any questions you have for your healthcare team before your appointments. Talk with your team to learn as much as you can about your diagnosis and treatment options. Be 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, 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.

Sometimes, fear of recurrence or progression may stop you planning for the future or living your life to the fullest.

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 on page 64.

Take a look at melanoma.org.au to download our Patient Information Brochures:

- How to cope with fear of melanoma returning
- Scanxiety
- Looking after yourself



Coping with the fear of recurrence or progression

While you can't 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 worry:

- **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 the same as you.
- **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 43 for advice on how to conduct 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 drinking.

If recurrence or progression happens

A recurrence or progression of your melanoma can trigger painful memories and emotions. You may feel distressed, angry or just plain exhausted! These are all normal reactions.

It's likely that the same coping or support mechanisms that worked for you during your first treatment will work this time around too. You can feel empowered by the knowledge that you have gained on your journey so far.

Stress

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

Some signs that you may be stressed include:

- feeling 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 or progression, it can make it harder to cope with everyday life.

Prolonged or chronic stress may impact on your everyday life, 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 or disease progression 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 these 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.

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 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 through it.
- **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 causing you concern, speak with your healthcare team about accessing counselling. You can read more about psychological support and counselling on page 64.

Genetics and melanoma

Melanomas themselves are not passed on from person to person but our risk of melanoma certainly is hereditary - it is strongly affected by our genetic background.

Rarely, a specific faulty gene that causes high 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 our moles, and other invisible effects of our genetic makeup.

If you are concerned about your genetic risk, speak to your healthcare team.

Anger

Being diagnosed with melanoma, or a progression of the disease, might make you angry. It's an inconvenient disruption to your life plans and it's common 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 is unpleasant – it can make you physically tense and tired. So don't let your 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.

Emotions and Cancer

Resource available from Cancer Council
cancercouncil.com.au
 13 11 20



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 your history of 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 are a burden to your family and carers
- your 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.

Managing loneliness

It can be normal to feel alone during and after treatment for melanoma. Perhaps you feel like no one around you truly understands what you are going through. Maybe you don't want to burden your loved ones with how you are feeling. Or maybe you feel too sick from treatment to get out and about with your family and friends.

At times like this, it's important to find someone who you can be completely open and honest with. This may be a loved one or it may be someone who has had a similar experience. There are a number of face-to-face, online and telephone peer-to-peer support services available throughout Australia for people affected by melanoma. Go to page 65 for more details.

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.

Talk to your healthcare team if you think you may have anxiety or depression.

There are programs, support groups and helplines that may be useful for you. Professionals such as psychologists or counsellors can provide you with strategies to help you cope with your situation. You can read more about accessing psychological support on page 64.

Living Well After Cancer

Resource available from Cancer Council
cancercouncil.com.au
 13 11 20



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

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.

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.

Your GP or the healthcare team managing your melanoma treatment can help to put you in touch with a psychologist or counsellor who can provide tailored support for you. Speak with your GP to see if you are eligible for Medicare rebates for some of these services.

You can also:

- visit 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](tel:131120) to find a psychologist specialising in cancer support in your area.

If you need immediate crisis support, call Lifeline on [13 11 14](tel:131114).

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.

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 Patients Australia melanomapatients.org.au

1300 884 450

Melanoma Patients Australia (MPA) provides a range of free specialist and lived-experience support options for people affected by melanoma — including patients, carers, and family members — throughout Australia.

Services include:

- 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**.

Cancer Council

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

Metastatic melanoma telephone support group (in conjunction with Melanoma Patients Australia)

A free national telephone support group for people with Stage III and IV melanoma.

To register or find out more:

1300 755 632

tsg@nswcc.org.au

Cancer Council Online Community onlinecommunity.cancerCouncil.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**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 is available to all melanoma patients and their carers.

Phone **1300 884 450** to book an appointment or visit melanomapatients.org.au.

Psychologists**Australian Psychological Society**psychology.org.au**1800 333 497****Lymphoedema****Lymphoedema Association Australia**lymphaustralia.org.au**1300 852 850****Nutrition****Dietitians Australia**dietitiansaustralia.org.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**Melanoma Patients Australia**melanomapatients.org.au**Cancer Council Australia**cancer.org.au**eviQ Patient and Carers**eviq.org.au/patients-and-carers**International websites****Macmillan Cancer Support**macmillan.org.uk**US National Cancer Institute**cancer.gov**American Cancer Society**cancer.org**MD Anderson Cancer Center**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

13 11 20

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 worried about losing 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

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

It's totally up to you how much or how little you want to share with your friends and family. When you feel ready to talk, the following tips may help you to have the 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 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.

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. Often, children are more resilient than we realise.

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

13 11 20

CanTeen

Information for young people between the ages of 12–25

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.

Take a look at melanoma.org.au to download our Patient Information Brochure called “Caring for a loved one with melanoma”.



Resources for carers

Caring for someone with cancer

Booklet available from Cancer Council 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.
- for people who have lost a love one within the past two years.

To register, call **13 11 20, 1300 755 632** or email tsg@nswcc.org.au.

Carers Australia

carersaustralia.com.au
1800 422 737

Access carer information, advisory and counselling services.

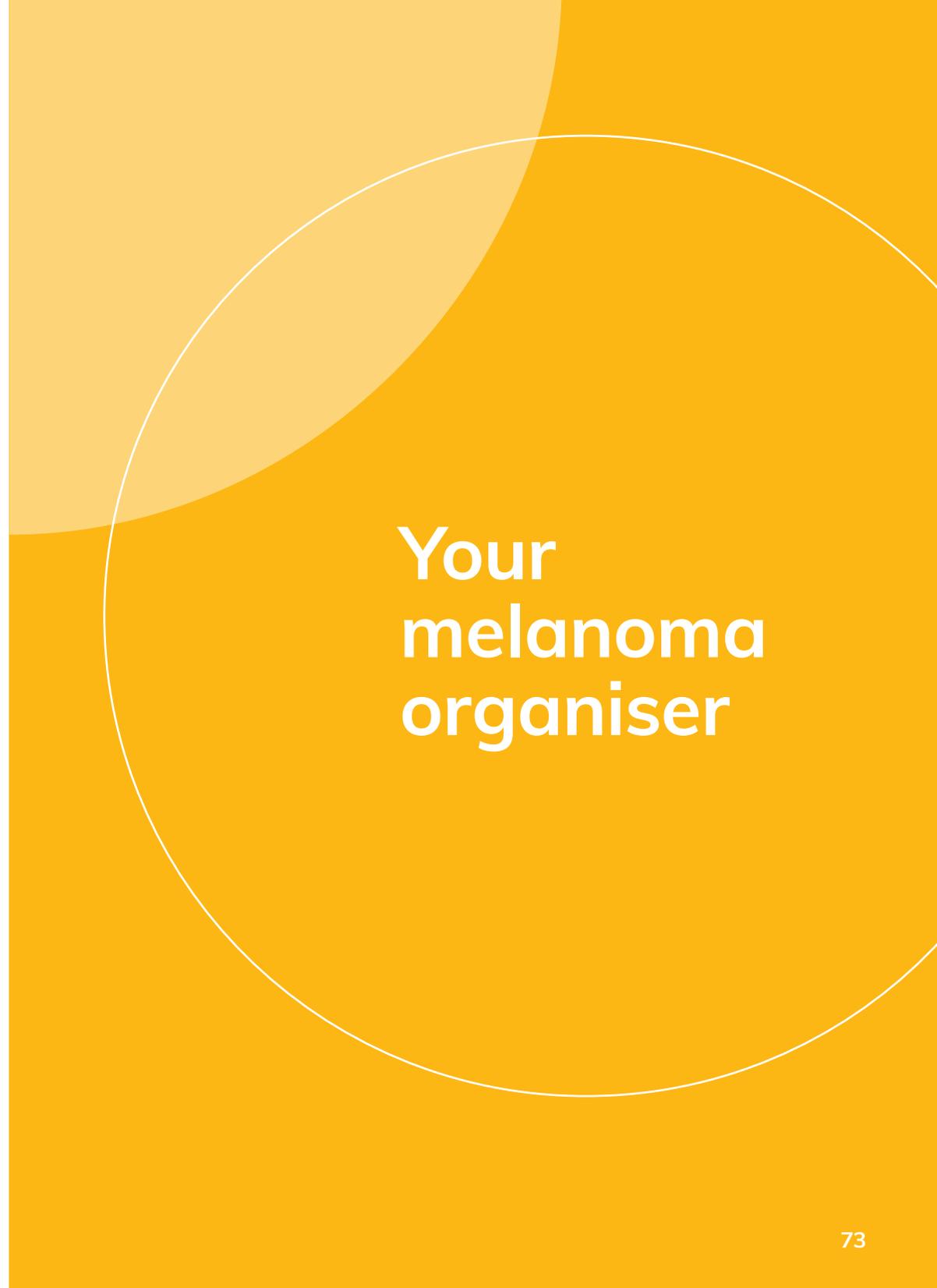
Young Carers

youngcarers.net.au

Access information, support and financial aid services.

Notes

Lined area for taking notes, consisting of horizontal dotted lines.



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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Medical information

Medical history

Record your past and current medial conditions here.

CONDITION	TREATMENT
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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

.....

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

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Notes on radiation therapy

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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

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Date of treatment

Type of treatment

Doctor

Purpose of treatment

Notes

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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

.....

.....

Body maps

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

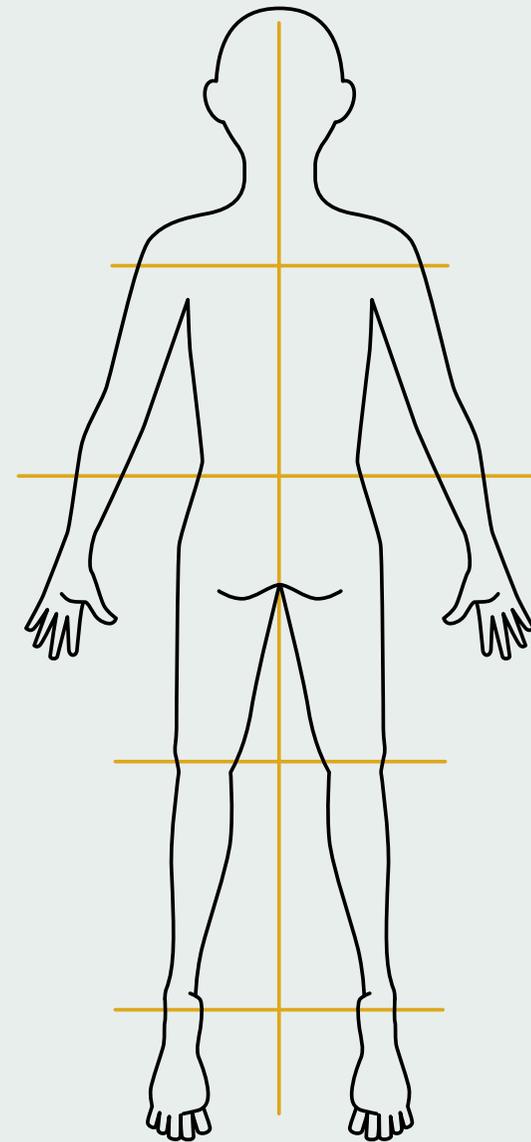
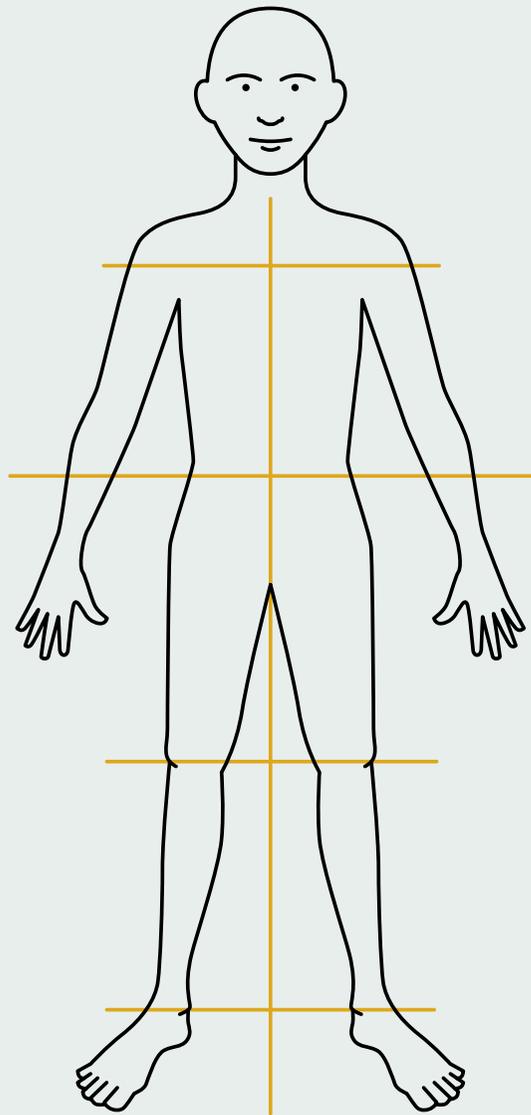
- 1/01/2025 – new, 2mm, brown
- 4/01/2025 – checked by doctor
- 1/04/2025 – no change
- 1/07/2025 – changed: 3mm, red spots, needs checking by doctor

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

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 or skin cancer doctor

A doctor who manages your screening, diagnosis and general health needs. Your GP may also 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

Address

.....Postcode

Phone..... Mobile

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Name

Occupation/Department

Address

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Phone..... Mobile

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Name

Occupation/Department

Address

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Phone..... Mobile

Notes

Name

Occupation/Department

Address

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Phone..... Mobile

Notes

My appointments

Appointment with

Date..... Time

Location

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Reason for appointment

Notes

Appointment with

Date..... Time

Location

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Reason for appointment

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Appointment with

Date..... Time

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Reason for appointment

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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

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 given after 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, and 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

A term used to describe 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).

Neoadjuvant

Additional treatment that is given before the main treatment (e.g. systemic therapy given before surgery).

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.

Acknowledgements

This book 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.

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