

Your Guide

to Stage IV Melanoma

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

Name

Mobile

Email

The purpose of this guide

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

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

Who is this guide for?

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

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:

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

Contents

About melanoma	3	Living with Stage IV melanoma	33
What is melanoma?	4	Attending medical appointments	34
The skin	5	Managing lymphoedema	35
How cancer grows and spreads	6	Sun protection	36
What is Stage IV melanoma?	8		
Diagnosing and staging melanoma	9	Self-care and support	39
Initial diagnosis	10	Looking after yourself	40
Biopsy	11	Your emotional wellbeing	44
Detecting melanoma in other areas of the body	14	Getting help and support	54
Staging melanoma	15	Your family and friends	58
Prognosis	17	Having end-stage melanoma	62
Treating Stage IV melanoma	19	Your melanoma organiser	65
An important note on treatment	20	Personal details	67
The approach to treating Stage IV melanoma	21	Medical information	69
Systemic therapy	22	My diagnosis summary	71
Radiation therapy	26	My treatment plan	72
Other treatment options	27	My follow-up plan	79
Clinical trials	29	My healthcare team	80
Palliative care	30	My appointments	83
		Medication chart	86
		Medical expenses	88
		My notes and questions	90
		Glossary	92

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, to make it easier for you to access reliable and expert information.

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

Regards,

Professor Georgina Long AO and Professor Richard Scolyer AO
Co-Medical Directors
Melanoma Institute Australia





About melanoma

What is melanoma?

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

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

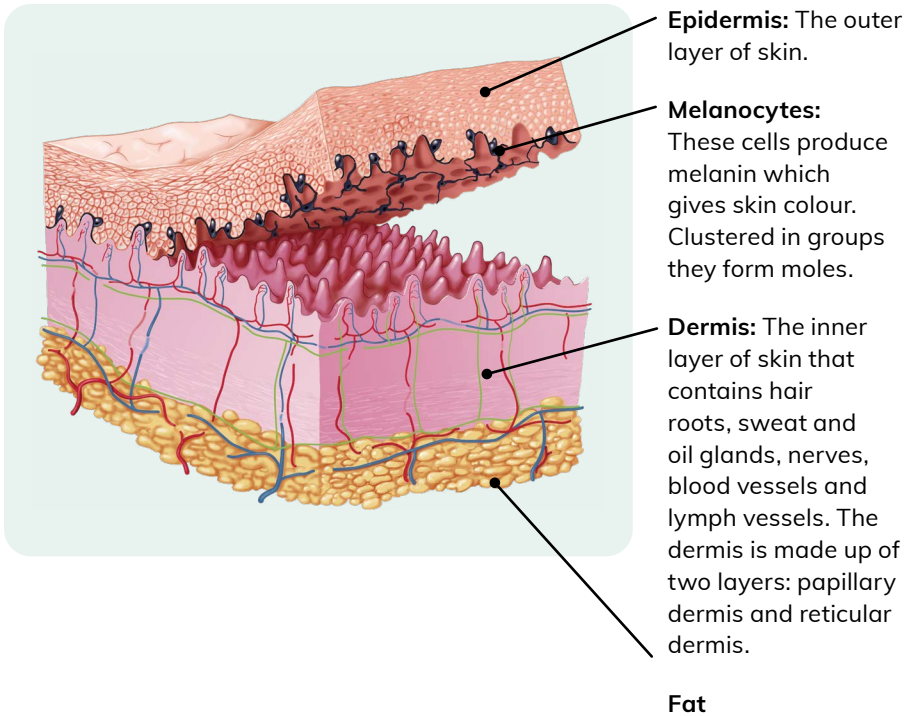
A primary melanoma is the site of origin of a melanoma.

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



On average, **46 Australians will be diagnosed with melanoma every day; that is close to one person diagnosed every 30 minutes.**

The skin

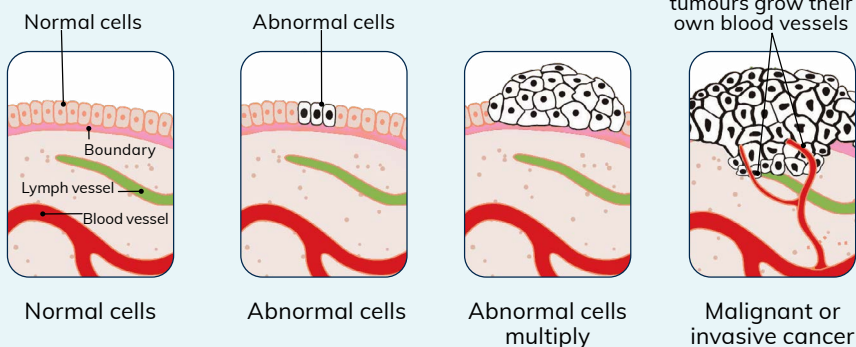


How cancer grows and spreads

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

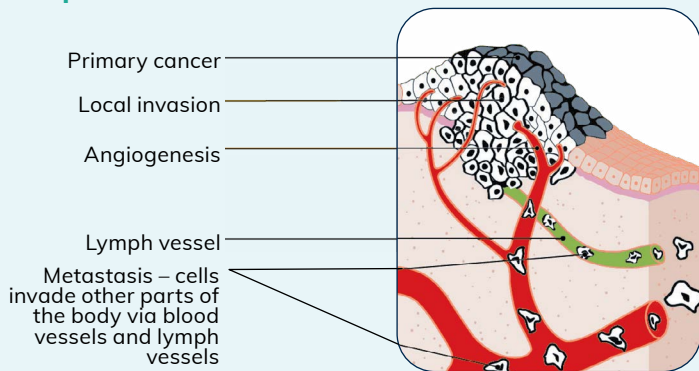
Cancer occurs when abnormal cells grow and divide in an uncontrolled manner, forming a tumour.

How cancer starts



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

How cancer spreads



Adapted from Cancer Council Victoria. Illustration by Paul Sloss.

What is Stage IV melanoma?

The stage of a cancer is used to describe 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 IV melanoma is melanoma that has spread to other parts of the body, distant from the original (primary) site. It is sometimes called advanced or metastatic melanoma.

Treatment for melanoma depends on a number of factors, including stage. You can read more about treatment for Stage IV melanoma on pages 19 to 30.

You can read more about each stage of melanoma on pages 15 and 16.



Diagnosis and staging melanoma

Initial diagnosis

Everyone's experience with melanoma is unique. In this section, we explore some of the procedures involved in diagnosing and staging a 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.

To diagnose a Stage IV melanoma, your healthcare team may have conducted:

- imaging tests, such as ultrasound or X-rays, to see how far the melanoma has spread through your body.
- biopsies, to remove tissue samples for testing (including genetic testing).
- blood tests, to look at your blood count and liver function.

Imaging tests

Imaging tests use different methods to create an image of your insides. Your doctor may have recommended one or more types of imaging tests to look for the spread of melanoma in your body.

- **Ultrasound** uses high frequency sound waves to look at internal structures. It is often used to look at smaller areas or specific organs of the body.

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

Biopsy

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

Your doctor may have recommended you have a biopsy of:

- a lesion or mole on your skin
- a lump underneath your skin
- a lymph node or nodes
- an internal organ or organs in your body.

Types of skin biopsy

If your doctor wanted to investigate a suspicious looking mole or lesion on your skin, you may have had one of these common types of skin biopsies.

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

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

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

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

Biopsy to look for melanoma spread

If your doctor wanted to investigate the spread of melanoma to lymph nodes or organs in your body, you may have had a fine needle (or core) biopsy of the suspicious area.

Fine needle / core biopsy. A needle biopsy may be used to investigate enlarged lymph nodes or a suspicious area in another organ. For this type of biopsy, a doctor inserts a needle, similar to that used for blood collection, into the suspicious lymph node or lump to collect a sample of cells. These biopsies are often performed by a radiologist with the use of an ultrasound or CT scan to safely guide them to the spot of the biopsy.

Following the biopsy, a pathologist would have examined your tissue sample under a microscope to determine if it contained melanoma cells. The results of your biopsy are used to inform your treatment plan.

Blood tests

While blood tests aren't used to diagnose melanoma, some routine blood tests may be done to help your healthcare team assess your prognosis and plan your treatment.

Before any treatment begins you may have blood tests to check your blood count, white cell count, kidney function, liver function and hormone levels. This gives your healthcare team baseline levels so that they can monitor for any changes in these levels while you are having treatment.

In particular, a blood test called lactate dehydrogenase (LDH) helps your specialist better understand your disease and potential prognosis.



Melanoma mutations

Some melanomas carry genetic mutations that make them susceptible to specific targeted therapies (see page 22).

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

Most genetic mutations in melanoma are sporadic. This means the mutation in the genes occurs by chance after a person is born, so there is no risk of passing on the genetic mutation to your children.

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.

Detecting melanoma in other areas of the body

Sometimes, melanoma can be found elsewhere in the body without ever finding the primary site on the skin. This is because a suspicious spot or lump on the skin can go away on its own after some of the cells have spread to other parts of the body.

If melanoma is detected in an organ, it can sometimes be confused with cancer starting in that organ. For example, a melanoma that has spread to the lung may be confused with a primary lung cancer. It is important to correctly identify the type of cancer, as it may respond differently to therapy depending on where it originated.

Laboratory testing on tissue samples can tell us whether a cancer is a melanoma or another type of cancer.

The most common parts of the body that Stage IV melanoma spreads to are the:

- lungs
- liver
- bones
- brain
- bowel.

Stage IV melanoma spread can appear many years after a primary melanoma was removed. Sometimes, Stage IV melanoma can be found in people with no history of a primary melanoma.

Staging melanoma

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

The stage of your melanoma helps to guide your treatment approach. In most cases, the stage of a cancer is based on three factors:

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

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

Stages of melanoma and likely treatment options

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 1 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"> – Surgical removal (wide local excision) for in-transit disease – Consideration of lymph node dissection (removal of all lymph nodes in the affected region) – Consideration of additional treatments before or after surgery, such as radiation therapy or drug (systemic) therapies
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

Prognosis

Recent advances in the treatment of Stage IV melanoma are offering real hope for patients. New treatment options are controlling melanoma, significantly extending life expectancy and resulting in a cure for some patients.

Melanoma Institute Australia is pioneering research into Stage IV melanoma, with new treatments being developed and tested all the time.

It is hoped that the number of people living well and free of melanoma after treatment will continue to increase in the years to come.

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

You may like to talk to a professional, such as a counsellor or psychologist, about your response to finding out about your prognosis. You can read more about accessing this support on page 54.

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

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?
- Does my melanoma have a genetic mutation which will impact my treatment options?
- Is it possible to cure or control my melanoma?



Treating Stage IV melanoma

An important note on treatment

The world of 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 success of clinical trials and approval of government bodies, such as the Therapeutic Goods Administration (TGA), which licenses drugs for use in Australia, and the Pharmaceutical Benefits Scheme (PBS), which subsidises the cost of certain drugs for patients.

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

We acknowledge that in this ever-changing environment, treatment options may change. As such, the content provided here 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.

The approach to treating Stage IV melanoma

New treatment options can significantly extend life in patients with Stage IV melanoma, and some patients are considered cured of their disease. Treatment for Stage IV melanoma also focuses on controlling symptoms and disease progression, prolonging life and optimising quality of life.

If you have been diagnosed with Stage IV melanoma you may be recommended to have a combination of different treatments, including:

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

Systemic therapies use the bloodstream to deliver drugs to the whole body.

Radiation therapy and surgery are local treatments. This means they only treat the specific area of the body affected by melanoma.

Some treatment options for Stage IV melanoma are explained on the following pages. You may have none, one or a combination of these treatments to manage your melanoma. You and your doctor will discuss a treatment approach that is best for you.

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. Read more on page 56 of this Guide or visit melanomapatient.org.au.



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.

There are two categories of systemic therapy most commonly used to treat melanoma: targeted therapy and immunotherapy.

Targeted therapy

Targeted therapy was one of the first of a new generation of treatments for melanoma that provided great hope to Stage IV patients.

Targeted therapies are drugs that identify and 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.

Targeted therapies selectively block the activity of these gene mutations, therefore blocking the growth of the cancer. Therapy will only be suitable for you if your melanoma has the specific gene mutation (see page 13.)

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")
- cKIT ("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 melanoma with BRAF mutations.

Currently, there are three targeted therapy regimens that are approved for use in Australia in patients with a BRAF-mutation. These regimens combine 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 combinations are:

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

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

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

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

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.

Immunotherapy

Different immunotherapies can be used to treat Stage IV melanoma.

Immunotherapy (also known as immune therapy) works by activating the body's own immune system to seek out and fight melanoma cells. Immunotherapy can be used to treat all types of melanoma of the skin, regardless of your genetic mutation test result, though not all patients respond to treatment.

Ipilimumab, nivolumab, pembrolizumab and relatlimab are the immunotherapies currently available in Australia for the treatment of Stage IV melanoma. They are all types of checkpoint inhibitors. Checkpoint inhibitors block proteins on the surface of melanoma cells that usually stop the body's immune system from killing the cancer cells. When these proteins are blocked, the immune system's ability to kill the cancer cells is increased.

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

Side effects of immunotherapy

Immunotherapy can sometimes cause your 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.

Understanding Immunotherapy

Resource available from Cancer Council:
cancercouncil.com.au



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.

Chemotherapy

Chemotherapy has become a less-considered option for Stage IV melanoma as newer therapies have been found to be much more effective.

Chemotherapy works by slowing or stopping the growth of the melanoma by destroying cells that are dividing rapidly. It may be used to slow the growth of cancer cells, or as a palliative treatment.

Side effects of chemotherapy

Chemotherapy can cause the following side effects:

- nausea
- vomiting
- depression
- tiredness
- hair loss.

These side effects are temporary, and steps can be taken to prevent or reduce them.

eviQ

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



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 IV 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.

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

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.

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.

Other treatment options

Surgery

Surgery may be an option for Stage IV melanoma if the cancer is present in only one or two sites.

Melanoma that has spread to other organs (metastases) can sometimes be removed with surgery, if they are accessible and causing symptoms.

Lymph node dissection

Surgery may also be performed to remove any lymph nodes that the melanoma has spread to. This is called a lymph node dissection.

Your healthcare team 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 dissection) or all the lymph nodes from the groin and pelvis (ilio-inguinal 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.

Lymphoedema is a potential side effect of lymph node dissection. You can read more about managing lymphoedema on page 35.

Observation

Sometimes people choose not to have any systemic treatment. Other times your oncologist may suggest observation if your melanoma is slow growing or the melanoma lesions are small and not in many places in your body. You will be closely monitored with scans and seen by your oncologist at regular intervals.

Visit melanoma.org.au for more information about lymph node dissection. Take a look at our Patient Information Brochures on each type of lymph node section, as well as exercises to help with recovery.



Clinical trials

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

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

If you are interested in participating in a clinical trial, your healthcare team may find a trial that is suitable for you.

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

Visit melanoma.org.au for more information on clinical trials and research studies.



Palliative care

It is often thought that palliative treatment is for people at the end of their life. However, it can be beneficial for people at any stage of advanced melanoma.

Palliative treatment aims to improve your quality of life by reducing cancer symptoms and making you more comfortable, without aiming to cure the disease. Research has shown that engaging early with a palliative care team can optimise your quality of life and disease management.

Be sure to have an open dialogue with your healthcare team about your symptoms to ensure that you are as comfortable as possible.

Palliative treatment can include:

- Assistance with managing symptoms, such as fatigue, appetite loss, constipation, pain or nausea.
- Strategies to slow the growth and spread of melanoma, such as radiotherapy or chemotherapy.
- Life planning and emotional support for you and your family.

Notes

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Support for you



Questions you may like to ask your healthcare team

- What are my treatment choices?
- What is the goal of my treatment?
- 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?



Living with Stage IV melanoma

Attending medical appointments

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

Attending medical appointments are a good way to monitor your health and to make sure that any concerns are dealt with quickly.

Appointment schedule

How often you visit your doctor depends on several factors, including the extent of your melanoma and your treatment plan.

People with Stage IV melanoma with evidence of disease following treatment will likely attend medical appointments more regularly, depending on your ongoing treatment or care.

People with Stage IV melanoma who have no evidence of disease following treatment will likely attend follow-up appointments less regularly.



Managing lymphoedema

If you have undergone a complete lymph node dissection as part of your treatment, you may experience lymphoedema.

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

You can expect some swelling around the wound and possibly in the affected limb in the first couple of months after your operation. This is not lymphoedema but simply part of the normal healing process and usually subsides on its own.

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

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

Radiotherapy can also increase the risk of lymphoedema. If you are going to have radiotherapy, you can ask your doctor for a referral to a lymphoedema specialist before you start your radiotherapy treatment. Your doctor can arrange Medicare cover for you to receive some financial assistance towards this appointment.

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

Visit melanoma.org.au to find out more.



Sun protection

Did you know that 95% of melanomas in Australia 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.

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



Seek shade, especially in the hottest part of the day.



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



Wear a broad-brimmed hat.



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



Wear wrap-around sunglasses.

Applying sunscreen

There are many different types of sunscreen. Choose one that you like the feel of enough to wear every day.

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.

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.

Make it a habit to apply sunscreen in the morning as part of your daily routine.

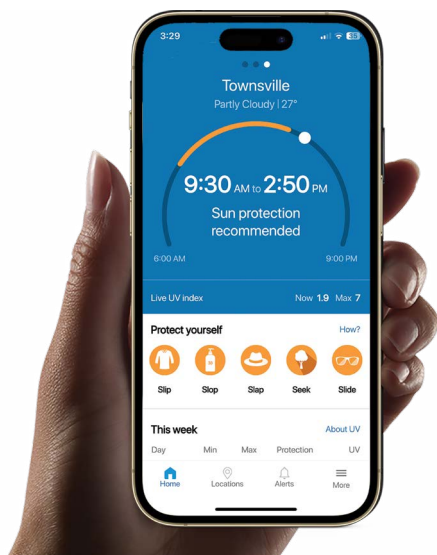
Wearing protective clothing

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

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

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.



UV Index

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.

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 forecasts.

A note on Vitamin D

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

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

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

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

Your vitamin D levels can be determined through a simple blood test and your GP may recommend vitamin supplements if you have low levels.



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 65.

Keeping active

Being physically active 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 – everyday if you can manage. Start slowly, listen to your body.

Exercise guidelines recommend participating in 30 minutes of aerobic activity three or more times a week, as well as two to three resistance exercise sessions each week. However, everybody is different. This level of activity may not be appropriate for you.

For example, if you have cancer affecting the brain, your balance may be affected. If you have undergone surgery, you should 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.

Patient Information Brochures on Exercise

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



An accredited exercise physiologist or physiotherapist can help you set up an exercise program that suits your body and needs.

You can find an accredited exercise physiologist at essa.org.au.

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 (APD) through the Dietitians Association of Australia at daa.asn.au or on 1800 812 942.

The 'Find an APD' button on the website allows users to search for dietitians with a specialty in cancer.

Smoking

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

Nutrition and Cancer



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

Quitline



If you need help quitting smoking, contact the Quitline on 13 78 48 or visit icanquit.com.au

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. Try to go to bed at the same time each night. Avoid caffeine and electronics, such as your phone, television or computer, close to bedtime. Instead, relax with a good book or some soft, calming music.



Doing activities that you enjoy

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

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

Finding a 'new normal'

Receiving a diagnosis of melanoma, or finding out your melanoma has spread, can be life changing. 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:

- **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.
- **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.

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.

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 57.

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.

Fear of progression

When you find out that you have melanoma that has spread to other parts of the body, it's very common to worry that the melanoma will spread further.

This fear of progression is completely normal, but it can be distressing and unpleasant. Sometimes, fear of progression may stop you living your life to the fullest.

Fear of progression is completely normal, but it can be distressing and unpleasant.

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 have been diagnosed with cancer
- when you notice a new sign or symptoms, such as new skin changes or aches and pains.

If you are finding it difficult to manage your fear of progression or if it's affecting your daily life, it may be time to seek additional counselling. You can read more about psychological support on page 54.



Coping with the fear of progression

While you can't control what the future holds, you can control how much fear of progression affects your daily life. Here are a few ways to manage your worry:

- **Join a support group** – It can be a big help to talk to other people who feel the same as you.
- **Be aware of symptoms** – It's important to be well informed about the signs and symptoms that may indicate your melanoma has spread to other areas. Talk with your healthcare team about signs and symptoms you should be mindful of.
- **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 your disease progresses

A 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 treatment so far will continue to be beneficial. You can feel empowered by the knowledge you have gained on your journey so far.

When there are no more treatment options

Sometimes, even with the best treatments and care, melanoma continues to spread.

At this point, you may choose to stop your active treatment, or your healthcare team may recommend it. Instead, you may choose to focus on your quality of life by reducing cancer symptoms and making yourself more comfortable. You can discuss your needs with your healthcare team, who can coordinate a service to assist you. You can read more about services that can help with this on page 30.

Managing loneliness

It can be normal to feel alone when you have Stage IV melanoma. Perhaps you feel like no one around you truly understands what you are going through. Or maybe you feel too sick from treatment to get out and about with your family and friends.

At times like this, it can help to speak with people who have 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 55 for more details.

Stress

Stress is the way your body reacts to a threatening or harmful situation. Being diagnosed with Stage IV melanoma 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 Stage IV melanoma can change the way you feel about yourself. There are a number of reasons for this.

- You may find that your treatment affects 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 find that you have a new perspective on life. Things that were important to you before your diagnosis may not feel as important now.
- For some people with late-stage melanoma, living with the fear of death or a shortened life expectancy can change your approach to life.

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 used to your new circumstance and context.

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 54.

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. Some people may feel angry that their melanoma has spread despite treatment efforts.

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 or boxing.

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.

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 moles we have and other invisible effects of our genetic makeup.

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

Anxiety and depression

A diagnosis of Stage IV melanoma is life-altering. 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 54.

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 Cancer Council on 13 11 20 to find a psychologist specialising in cancer support in your area.

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

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 Institute Australia
melanoma.org.au

(02) 9911 7200

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

Melanoma Patients Australia
melanomapatients.org.au

1300 884 450

In addition to running face-to-face or virtual support groups, Melanoma Patients Australia (MPA) provides a range of support options throughout Australia, including:

- one-on-one telephone support where you can speak with a person who understands your experience and can provide you with helpful information
- connecting you with other patients that have shared a similar lived experience (peer-to-peer linkages).

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 Information and Support Line

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.

13 11 20

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

Cancer Connect

02 9334 1870 or 13 11 20

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

Melanoma Nurse Telehealth Service

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

Phone 1300 884 450 to book an appointment or visit melanomapatients.org.au to find out more.

Psychologists

Australian Psychological Society

psychology.org.au

1800 333 497

Lymphoedema

Australasian Lymphology Association

lymphoedema.org.au

admin@lymphoedema.org.au

Exercise

Exercise and Sport Science Australia

essa.org.au

07 3171 3335

Nutrition

Dietitians Australia

daa.asn.au

1800 812 942

Finding information online

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

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

General Australian websites:

Melanoma Institute Australia

melanoma.org.au

Melanoma Patients Australia

melanomapatients.org.au

Cancer Council Australia

cancer.org.au

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 this time.

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

Talking about dying and death

If you have end-stage melanoma, one of the hardest things can be sharing that news with your loved ones.

Some people choose to talk openly about death with their family and friends, while others prefer not to discuss it at all. Both approaches are completely normal.

Talking about death can help you feel less isolated and distressed. And it can also provide comfort to your loved ones who are grieving with you. You may choose to talk about your wishes for end-of-life care, plans for your funeral and your hopes for them after you are gone.

If you choose to discuss death and dying with young children, it is important to remember that children of different ages have different ideas about the permanence of death.

Understanding Melanoma – A Comic Book for Kids



Online resource available from
Melanoma Institute Australia
melanoma.org.au

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 their loved one to frustration or stress about their situation.

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

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

Information and support resources

Caring for someone with cancer
cancercouncil.com.au
13 11 20

Booklet available from Cancer Council.

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 loved one within the past two years.

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

Carer Gateway
carergateway.gov.au
1800 422 737

Carer Gateway is an Australian Government program providing free services and support for carers.

Carers Australia
carersaustralia.com.au
02 6122 9900

Access carer information, advisory and counselling services.

Young Carers Network
youngcarersnetwork.com.au

Access information, support and financial aid services.

Having end-stage melanoma

When melanoma can no longer be controlled, active treatment may be stopped. You may be told you have end-stage or terminal melanoma.

It can be confronting and overwhelming to hear that you are facing death. The way you approach this challenging time will be deeply personal, and may be influenced by your age, family situation, culture and spiritual beliefs.

How you may be feeling

Everyone reacts to the news that they are dying in different ways.

At first, you may feel shocked, even if you were expecting the news. Some people cry. Some people are silent and do not know what to say. Others feel angry or scared. These are all normal first reactions.

As time passes, you may feel scared, angry, helpless, worried or denial – or you may feel all these emotions at once. These emotions can be overwhelming and too painful to cope with. This is normal and entirely understandable.

You may find your emotions change over time as you process what is happening. While feelings of worry or fear may never really go away, they may lessen in intensity and become more bearable.

Ways to cope

You may feel like you should accept or 'make peace' with the news that you are dying. But it's ok to feel sad and angry that this is happening to you. While there is no one 'best way' to cope with this situation, you may find some comfort in the following strategies.

- **Find someone to talk to** – Try talking with a close family member or friend about how you are feeling. Sometimes this can be difficult as you may not want to burden your loved ones or you may feel that they do not understand what you are going through. If you would prefer, you can speak with a professional counsellor or psychologist. You can read more about accessing psychological support on page 54.
- **Take things one day at a time**
 - The emotions you are feeling can be overwhelming and at times it may feel like you can't function. Make small and achievable plans that you can tackle one day at a time.
- **Write down your thoughts**
 - Keeping a journal can be a helpful way to process your emotions and feel in control of your situation. You may also find it helpful to write down things you wish to talk about with your loved ones.
- **Look after yourself** – Focus on the quality of your life. Take time to rest when needed and make a point to do the things you love the most.
- **Get in touch with what really matters to you** – Do the things you value and be the person you want to be.
- **Reflect on how you would like to prepare for the end of life**
 - People vary from preparing as much as possible for their death (e.g. funeral planning and wishes for their final days) to not doing any preparation at all. Do what feels right for you.
- **Consider leaving a legacy** – Some people find it helpful to think about leaving a legacy, such as writing letters to loved ones or making memory books.
- **Saying goodbyes** – Reflect on whether you want to say goodbye to loved ones in your life and how you would like to do it. This is a personal preference and may not be something you want to do.

Formalising your financial and health decisions

Organising your financial and legal affairs will ensure that you are able to protect your assets and provide for the people you care about in the way you want.

It will also ensure that the people you choose are able to make decisions for you about your health and finances, should you no longer be able to do so.

Making a will

A will is a legal document that outlines how you would like your property and possessions (your estate) to be distributed after your death. If you do not have a will, a formula is used to divide your estate among certain family members, which may not represent your wishes.

Power of attorney – general and enduring

A power of attorney is a legal document that names a person you have chosen to manage your legal and financial matters.

A general power of attorney can be useful if, for example, you are in hospital and you need someone to access your bank account on your behalf. It ends if you lose the ability to make decisions for yourself (mental capacity).

An enduring power of attorney stays in place and allows another person to manage your financial and legal affairs if you do lose the ability to make decisions for yourself.

A power of attorney does not give this person the ability to make medical decisions for you.

Facing End of Life

A guide for people dying with cancer, their families and friends.

Resource available from
Cancer Council

cancercouncil.com.au
13 11 20





**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
.....
.....
.....
.....
.....
.....
.....

Medical information

Medical history

Record your past and current medial conditions here

CONDITION	TREATMENT

Medications

Known allergies (e.g. aspirin, penicillin, peanuts)

My diagnosis summary

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

Date of biopsy

Doctor who took the biopsy

Location/s on my body

Results

Breslow thickness (mm)

Level of invasion (Clark)

Ulceration ☐ Yes/present ☐ No/absent

Mitotic rate

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

Sentinel Node Biopsy

My melanoma is Stage

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

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

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

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

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

My treatment plan

Systemic therapy

Date of treatment

Type of treatment

Doctor

Nurse

Dosage

Purpose of treatment

Notes

.....

.....

Date of treatment

Type of treatment

Doctor

Nurse

Dosage

Purpose of treatment

Notes

.....

.....

Date of treatment

Type of treatment

Doctor

Nurse

Dosage

Purpose of treatment

Notes

.....

.....

Date of treatment

Type of treatment

Doctor

Nurse

Dosage

Purpose of treatment

Notes

.....

.....

Date of treatment

Type of treatment

Doctor

Nurse

Dosage

Purpose of treatment

Notes

.....

.....

Date of treatment

Type of treatment

Doctor

Nurse

Dosage

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

Notes on radiation therapy
.....
.....
.....
.....
.....
.....
.....

Surgery

Use this space to record any surgery you have had for your melanoma in the past, or any planned surgery.

Date

Surgeon / Doctor

Hospital

Contact number

Type of surgery

Notes on surgery

.....

.....

.....

.....

Date

Surgeon / Doctor

Hospital

Contact number

Notes on surgery

.....

.....

.....

.....

Planned? ☐ Yes ☐ No

Location of treatment

Treatments _____

Doctor's name _____

Contact details

Clinical trials co-ordinator _____

Contact details _____

Notes

Supportive care

- ☐ Physiotherapist ☐ Dietitian
- ☐ Psychologist/psychiatrist ☐ Support group ☐ Palliative care team
- ☐ Others

Notes

.....

.....

.....

.....

.....

.....

.....

Complementary therapies...

.....

.....

.....

.....

.....

.....

.....

My follow-up plan

Tests or visits

Clinical skin examinations

How often?

Doctor

Scans

Which scans?

How often?

Doctor

Blood tests

How often?

Doctor

Notes

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

My healthcare team

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

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

General practitioner

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

Dermatologist

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

Pathologist

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

Surgeon

A doctor who operates to remove the melanoma.

Plastic surgeon

A doctor who specialises in reconstructive surgery.

Medical oncologist

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

Radiation oncologist

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

Clinical nurse consultant

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

Clinical trials co-ordinator

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

Oncology social worker

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

Psychologist

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

Physiotherapist

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

Palliative care team

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

Name

Occupation/Department

Address

.....Postcode

Phone..... Mobile

Notes

Name

Occupation/Department

Address

.....Postcode

Phone..... Mobile

Notes

Name

Occupation/Department

Address

.....Postcode

Phone..... Mobile

Notes

Name

Occupation/Department

Address

..... Postcode

Phone..... Mobile

Notes

Name

Occupation/Department

Address

..... Postcode

Phone..... Mobile

Notes

Name

Occupation/Department

Address

..... Postcode

Phone..... Mobile

Notes

My appointments

Appointment with

Date Time

Location

Reason for appointment

Notes

Appointment with

Date Time

Location

Reason for appointment

Notes

Appointment with

Date Time

Location

Reason for appointment

Notes

Appointment with

Date Time

Location

Reason for appointment

Notes

Appointment with

Date Time

Location

Reason for appointment

Notes

Appointment with

Date Time

Location

Reason for appointment

Notes

Appointment with

Date Time

Location

Reason for appointment

Notes

Appointment with

Date Time

Location

Reason for appointment

Notes

Appointment with

Date Time

Location

Reason for appointment

Notes

Medication chart

Keep track of your medication using the chart below.

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

MEDICATION	DIRECTIONS	NOTES
Maxolon	Take 1 tablet 1 hour before food	For nausea

As needed

Medical expenses

[illegible]

My notes and questions

Getting the best information from your healthcare team

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

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

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

Glossary

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

Adjuvant

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

Atypical moles

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

Benign

Not cancerous.

Cutaneous melanoma

Melanoma that starts in the skin.

Dermis

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

Epidermis

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

In-situ melanoma

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

Cancerous.

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 occur anywhere on the body, including the skin under the fingernails, eyes, mouth, nasal passages, genitals and even the soles of the feet or palms of the hands.

Metastatic melanoma

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

Naevus

Medical term for mole, birthmark or beauty spot.

Prognosis

The likely outcome or course of a disease.

Recurrence

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

Sentinel node biopsy

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

Staging

Staging a melanoma means that the doctor will try to determine the extent of the spread of the disease and whether or not it has moved from the original position on the skin to the lymph nodes or through the bloodstream into other parts of the body.

Systemic therapy

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

Tissue

A group of similar types of cells, as well as the substances that surround them. These include the skin, nerve tissue and muscle tissue.

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. noted 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.

Disclaimer

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



The Poche Centre
Camberaygal Land
40 Rocklands Road
Wollstonecraft NSW 2065
Australia

P 02 9911 7200
F 02 9954 9290
E info@melanoma.org.au

melanoma.org.au

