



Your Guide

Stage IV Melanoma

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The contents of this book are personal and confidential.

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The purpose of this guide

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

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

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

Who is this guide for?

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

Note to reader:

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

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

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

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





About melanoma

What is melanoma?

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

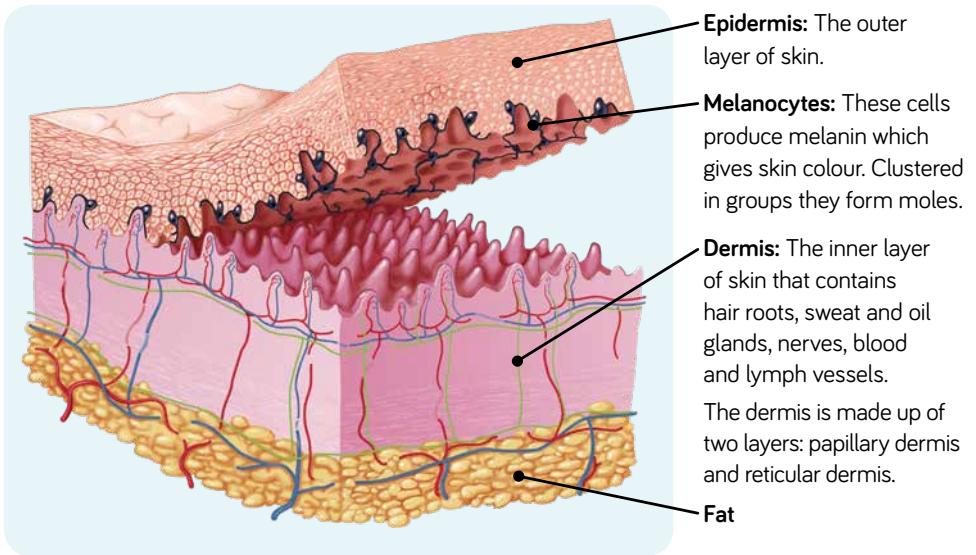
While melanoma usually begins in the skin (cutaneous melanoma), less commonly it can start in the eye (ocular melanoma) or the moist tissue that lines certain parts of the inside of your body (mucosal melanoma). It can occur anywhere you have melanocytes, even if they are not exposed to sunlight.

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



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

The skin



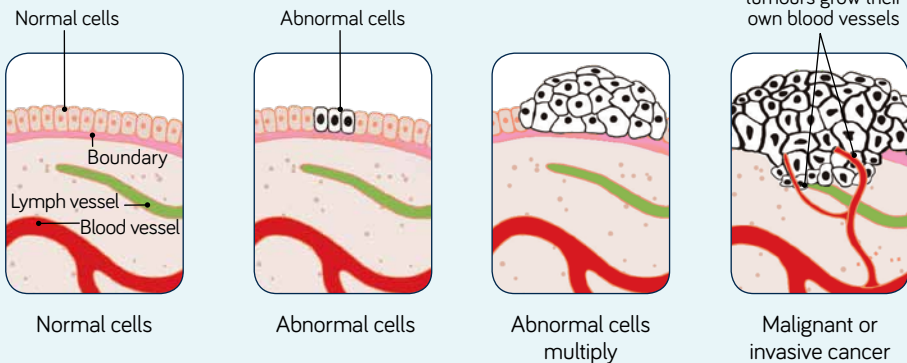
On average, **38 Australians** will be diagnosed with melanoma every day.

How cancer grows and spreads

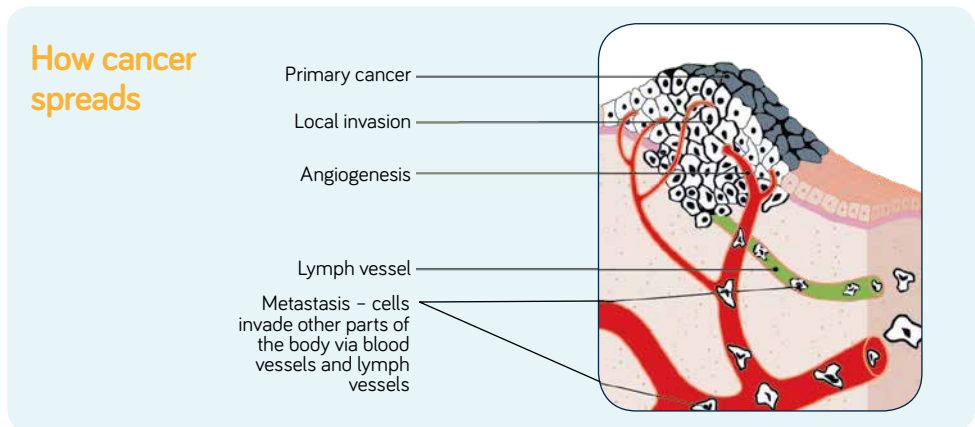
The body is made up of billions of cells that form tissues and organs. Healthy cells grow and duplicate in a controlled way, replacing old and damaged cells as the body requires.

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

How cancer starts



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



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.

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

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 36.



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

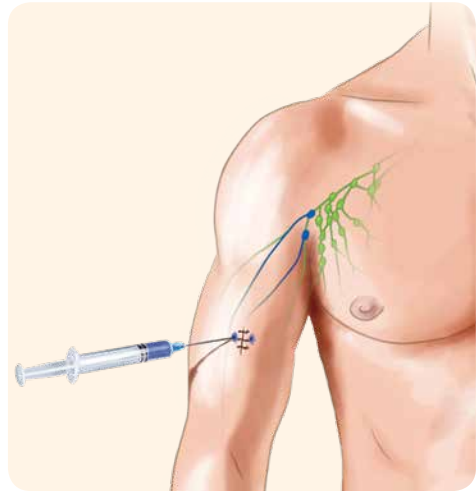
Types of biopsies to look for melanoma spread

If your doctor wanted to investigate the spread of melanoma to lymph nodes or organs in your body, you may have had one or more of these common types of biopsies.

Fine needle biopsy. A fine needle biopsy may be used to investigate enlarged lymph nodes or a suspicious lump. 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.

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



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.

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 your biopsy are used to inform your treatment plan.

You can read more
about Sentinel
Node Biopsy at
melanoma.org.au



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 23).

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.

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
- stomach or abdomen.

Stage IV melanoma spread can appear many years after a primary melanoma was removed.

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
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 - 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"> - Surgery or drug therapy may be used - Radiation therapy may also be considered

Prognosis

While there is no guarantee of a cure for Stage IV melanoma, new treatment options are significantly extending life in many patients. Additional treatments are being developed and tested all the time and there is new hope for patients with Stage IV disease. Melanoma Institute Australia is at the forefront of this research and committed to finding new treatment options.

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 48.

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

Support for you



Questions you may want to ask your healthcare team

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



Treating Stage 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

While there is no cure for all patients with Stage IV melanoma, new treatment options are significantly extending life in many patients. Treatment for Stage IV melanoma focuses on controlling symptoms, 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.

Surgery and radiation therapy 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 and your loved ones.

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 used to treat melanoma: targeted therapy and immunotherapy.

Targeted therapy

Targeted therapy was the first wave of a new generation of treatment for melanoma that has 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. Therefore, therapy will only be suitable for you if your melanoma has the specific gene mutation (see page 13.)

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

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

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

Currently, there are two 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.

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

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

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

eviQ

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



Side effects of targeted therapies

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

Other side effects may include:

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

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

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



Immunotherapy

Different immunotherapy 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 and pembrolizumab 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.

Understanding Immunotherapy

Resource available from Cancer Council:
cancercouncil.com.au



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:

- mouth sores
- skin problems (redness, dry skin, rash, blistering)
- flu-like symptoms (feeling tired, fever, weakness)
- diarrhoea
- cough.

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.

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. Radiation therapy is sometimes used in Stage IV melanoma on tumours or enlarged lymph nodes that are causing symptoms. It can be used to treat melanoma or to alleviate pain (palliative care).

Normal cells can repair damage to their DNA, but cancer cells are less able to do this and therefore die with 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, before or after surgery, or in combination with drug therapy.

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

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

Side effects of radiation therapy

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

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

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

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



Other treatment options

Surgery

Surgery may be an option for Stage IV melanoma if the cancer is present in only one or two sites. You can read more about surgery for melanoma in the Your Guide to Stage III Melanoma available at melanoma.org.au.

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

Metastases that cannot be removed with surgery may be treated with radiation therapy, systemic therapy or chemotherapy.

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

Visit melanoma.org.au for more information about 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.

Lymphoedema is a potential side effect of lymph node dissection. You can read more about managing lymphoedema on page 39.

Chemotherapy

Chemotherapy has become a less-considered option for Stage IV melanoma as newer therapies that are focused on the genes of melanoma cells have been found to be a much more effective treatment.

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.

Organ directed drug therapies

Melanoma that has spread to the liver may be treated with organ-directed drug therapies called intra-arterial chemotherapy or SIR-spheres.

Intra-arterial chemotherapy is given by inserting a catheter into the femoral artery in the right groin. The catheter is then guided by a CT machine into your liver. Chemotherapy is injected via the catheter straight into the liver. Most of the chemotherapy is contained in the liver and because of this causes few side effects on the rest of the body. Common side effects are abdominal pain, mild nausea and bleeding. These can be managed with medication. The treatment is given every second week initially.

SIR-spheres are radioactive beads that are injected into the liver in a similar way to intra-arterial chemotherapy. The beads are active for three months and aim to damage tumour cells in the liver with few side effects on surrounding tissue. Common side effects are abdominal pain, mild nausea and bleeding. These can be managed with medication. The treatment is normally given as a one-off dose but can be repeated if needed.

Both these procedures are performed by an interventional radiologist and require overnight admission to hospital.

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.

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.

Your healthcare team can use the Melanoma Institute Australia ClinTrial Refer Melanoma App to find the best possible clinical trial options available.

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

Understanding Clinical Trials and Research

Resource available from Cancer Council:
cancercouncil.com.au



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.

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.

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

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 doctor's appointments

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

Attentive medical care is important during treatment for Stage IV melanoma to monitor for further spread of the disease or a new primary melanoma.

Attending doctor's appointments is 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 doctor's 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



A healthy lifestyle

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

Maintain your doctor visits

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

Exercise

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

Rest

Be realistic about how active you can be during and after your treatment. If your procedures involve extensive surgery, you will need time to heal. Systemic therapy and radiation therapy can cause fatigue. Allow yourself time to rest when you need to.

Exercise is
Medicine
Australia

exerciseismedicine.org.au/public



Find an accredited
exercise
physiologist at

essa.org.au



Diet

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

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

Dietitians Association of Australia

daa.asn.au
1800 812 942



Nutrition and Cancer

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



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.

Quitline

If you need help
quitting, contact the
Quitline on 13 7848 or
visit quitnow.gov.au



Sun protection

Protecting yourself from the sun with sunscreen, protective clothing, sun shade and sun avoidance are important even after you have been diagnosed with melanoma. Some treatments for melanoma can make your skin more sensitive to the sun. It's important to discuss appropriate sun protection with your healthcare team.



Choosing sunscreen

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

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

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

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

Applying sunscreen

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

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.

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.

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.

Coping and emotional wellbeing

Everyone deals with diagnosis and treatment of melanoma differently. Being diagnosed with Stage IV melanoma will undoubtedly have a big impact on your life, and the life of your loved ones.

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

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

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

Emotions and Cancer

Resource available from Cancer Council:
cancercouncil.com.au



Australian Psychological Society

Find a psychologist at:
psychology.org.au
1800 333 497



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.

Advanced health directives

An advanced health directive (sometimes called a living will) is a written statement that sets out your preferences about your health and treatment if you are no longer able to make these decisions or speak for yourself.

Enduring guardianship

An enduring guardianship is a written statement that names a person who you have chosen to make medical and lifestyle decisions on your behalf if you lose the ability to do this for yourself.

Useful state-based resources

These websites provide more information about financial and legal matters related to your health.



NSW

planningaheadtools.com.au

QLD

justice.qld.gov.au/justice-services/guardianship

WA

health.wa.gov.au/advancehealthdirective/home

National

respectingpatientchoices.org.au

Seeking support

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

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

Melanoma Institute Australia

melanoma.org.au

(02) 9911 7200

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

Melanoma Patients Australia

melanomapatients.org.au

1300 884 450

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

melanomaWA

melanomawa.org.au

(08) 9322 1908

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

Support is not the same for everyone

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

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

Cancer Council Australia

cancer.org.au

Cancer Council Helpline: 13 11 20

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

Cancer Connections

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

Cancer Connect

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

Other useful websites

American Cancer Society

cancer.org

MD Anderson Cancer Center

mdanderson.org

MacMillan Cancer Support

macmillan.org.uk

Information and support for loved ones

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

Young people

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

Talking to kids about cancer

Booklet available from Cancer Council

cancercouncil.com.au

13 11 20

CanTeen

Information for young people between the ages of 12–25

'Dealing with your parent's cancer' booklet available

canteen.org.au

1800 226 833

Carers

Caring for someone with cancer

Resource available from Cancer Council

cancercouncil.org.au

13 11 20

Carers Australia

carersaustralia.com.au

(02) 6122 9900

Young Carers

youngcarers.net.au

1800 242 636



Your melanoma organiser

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

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

Personal details

Name

Address

City State Postcode

Phone Mobile

Email

In case of emergency

Emergency contact 1

Name

Address

City State Postcode

Phone Mobile

Relationship

Emergency contact 2

Name

Address

City State Postcode

Phone Mobile

Relationship

Healthcare cards

Medicare card number

Expiry

Healthcare concession card number (if applicable)

Expiry

Health insurance company (if applicable)

Policy number..... Level of cover

Patient identification numbers

INSTITUTION/HOSPITAL	PATIENT IDENTIFICATION NUMBER
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Medical information

Medical history

Record your past and current medical conditions here

CONDITION	TREATMENT

Medications

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

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My diagnosis summary

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

Date of biopsy

Doctor who took the biopsy

Location/s on my body

Results

Breslow thickness (mm)

Level of invasion (Clark)

Ulceration Yes/present No/absent

Mitotic rate

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

Sentinel Node Biopsy

My melanoma is Stage

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

BRAF status mutant/positive wild-type/negative

NRAS status mutant/positive wild-type/negative

cKIT status mutant/positive wild-type/negative

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

My treatment plan

Systemic therapy

Date of treatment

Type of treatment

Doctor

Nurse

Dosage

Purpose of treatment

Notes

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Date of treatment

Type of treatment

Doctor

Nurse

Dosage

Purpose of treatment

Notes

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Date of treatment

Type of treatment

Doctor

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Dosage

Purpose of treatment

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Purpose of treatment

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Date of treatment

Type of treatment

Doctor

Nurse

Dosage

Purpose of treatment

Notes

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Radiation therapy

Planned? Yes No

Radiation oncologist

Radiation received at

Contact number

Number of treatments planned

Start date..... Finish date

Number of treatments received

Dose received

Areas treated

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Notes on radiation therapy

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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

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Date

Surgeon / Doctor

Hospital

Contact number

Notes on surgery

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Clinical trials

Planned Yes No

Name of clinical trial

Location of treatment

Treatments

Doctor's name

Contact details

Clinical trials co-ordinator

Contact details

Notes

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Supportive care

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

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Complementary therapies

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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

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My healthcare team

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

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

General practitioner

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

Dermatologist

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

Pathologist

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

Surgeon

A doctor who operates to remove the melanoma.

Plastic surgeon

A doctor who specialises in reconstructive surgery.

Medical oncologist

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

Radiation oncologist

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

Clinical Nurse Consultant

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

Clinical trials co-ordinator

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

Oncology social worker

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

Psychologist

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

Physiotherapist

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

Palliative care team

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

Name

Occupation/Department

Address

..... Postcode

Phone..... Mobile

Notes

Name

Occupation/Department

Address

..... Postcode

Phone..... Mobile

Notes

Name

Occupation/Department

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Occupation/Department

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Phone..... Mobile

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Occupation/Department

Address

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Phone..... Mobile

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My Appointments

Appointment with

Date Time

Location

Reason for appointment

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Appointment with

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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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Appointment with

Date Time

Location

Reason for appointment

Notes

Medication chart

Keep track of your medication using the chart below.

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

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

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

Medical expenses

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

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

My notes and questions

Getting the best information from your health care team

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

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

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

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A series of horizontal dotted lines for writing notes.

Glossary

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

Adjuvant

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

Atypical moles

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

Benign

Not cancerous.

Biological therapy

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

Cutaneous melanoma

Melanoma that starts in the skin.

Dermis

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

Epidermis

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

In-situ 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

The cancer is locally invasive and grows destructively. It also may metastasise (spread) through the body. Malignant cells can also spread to other parts of the body through the blood and lymph systems.

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 prediction of the probable 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.

Disclaimer

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