Your Guide
to Early Melanoma

Melanoma
Institute Australia

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

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The purpose of this guide

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

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

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 early stage melanoma or would like more information about melanoma, then this guide is for you.

Note to reader:

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

Contents

Foreword

This patient support guide has been made possible through the support of Johnson & Johnson Pacific and Neutrogena®.

As a trusted partner of Melanoma Institute Australia, we hope that this support guide will be seen as a valuable resource by you and the team of professionals looking after you.

In today's multi-media world there is no shortage of information available on melanoma and what to expect. When receiving a diagnosis of melanoma, finding the right information that you can trust is extremely important.

The Melanoma Institute Australia has developed this guide and a comprehensive website, **www.melanoma.org.au**, to make it easier for you to access reliable and expert information.

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

We at Neutrogena® feel privileged to be able to support patient education that has been developed by world leading experts and we wish you a rapid recovery.

THE TEAM AT NEUTROGENA®

Melanoma Institute Australia | Neutrogena®

Introduction

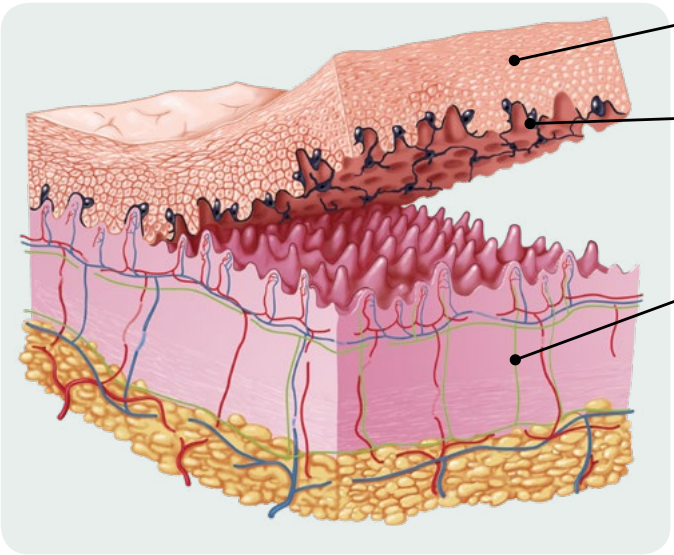
What is melanoma?

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

While melanoma usually begins in the skin, less commonly it can also start in the eye or mucosa (moist tissue that lines certain parts of the inside of your body). It can occur anywhere you have melanocytes.

Australia and New Zealand have the highest rates of melanoma in the world.

The skin



Epidermis: The outer layer of skin.

Melanocytes: These cells produce melanin which gives skin colour. Clustered in groups they form moles.

Dermis: The inner layer of skin that contains hair roots, sweat and oil glands and nerves and blood and lymph vessels.

Almost 14,000 new cases of melanoma are diagnosed every year in Australia. 90% of people will be treated successfully by having the primary melanoma surgically removed.

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

What is early stage melanoma?

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

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

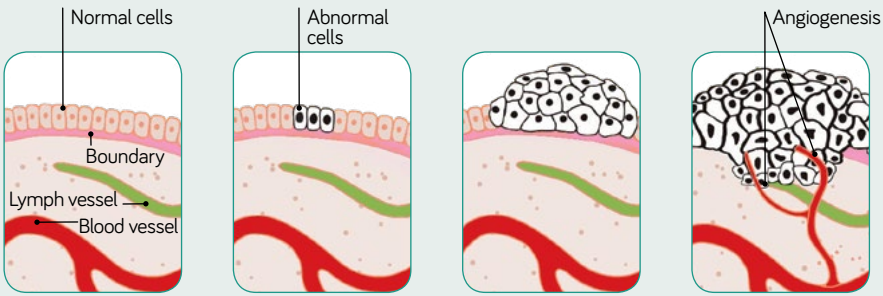
Stage 0 is very early stage melanoma, also known as in-situ melanoma. This means the melanoma is confined to the top layer of skin (epidermis) and has not spread to the deeper layer of skin (dermis). Lentigo Maligna (Hutchinson's melanotic freckle) is a type of in-situ melanoma.

You can read more about each stage of melanoma on pages 14–15.

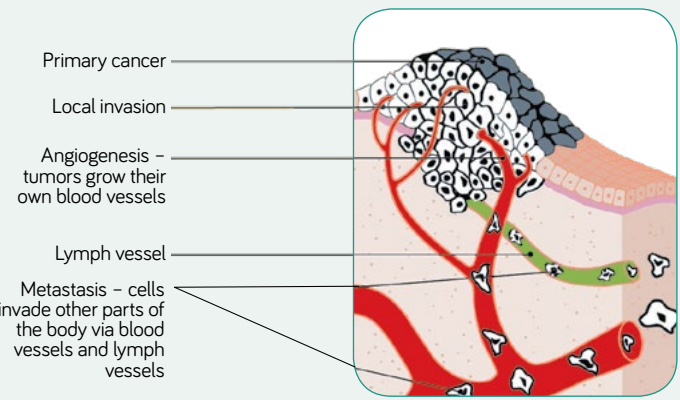
Treatment for melanoma depends on a number of factors, including stage. You can read more about treatment for melanoma on pages 17–22.

How cancer grows and spreads

How cancer starts



How cancer spreads



Adapted from Cancer Council Victoria. Illustration by Paul Sloss.

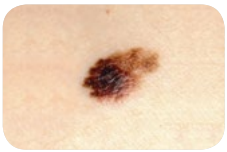
Notes

Diagnosis and treatment of melanoma

Types of melanoma

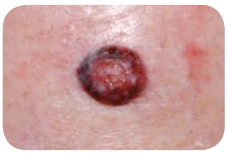
There are different types of melanoma and your pathology report will outline how your melanoma is classified.

Superficial spreading melanoma



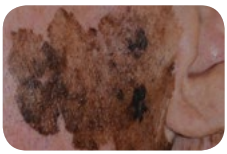
This is the most common type of melanoma making up more than 50% of all melanomas diagnosed. This melanoma usually appears as a dark spot with irregular borders that spreads across the skin.

Nodular melanoma



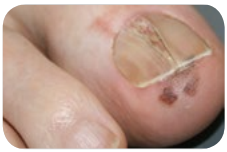
Nodular is one of the most rapidly growing types of melanoma. It appears as a raised lump or 'nodule' and can be brown, black, pink or red in colouring, or have no colour at all. About 15% of all melanomas are nodular.

Lentigo maligna melanoma



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

Acral lentiginous melanoma



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

Other, less common types of melanoma include desmoplastic and naevoid melanoma. Mucosal melanomas can be found in tissues in the respiratory, digestive, and reproductive tracts. Uveal (ocular) melanomas develop in the eye.

Pathology results

Your pathology report will have a detailed description of your tissue sample and may look similar to the example shown on the following page. Your doctor will explain what your results mean and how this will determine further procedures or treatment recommendations.

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

How long do pathology reports take?

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

The parts of a pathology report

Macroscopic description

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

Microscopic description

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

The specimen type refers to the type of sample that was taken from you, whether a shave, punch, incision, excision or fine needle biopsy. Site is the area on your body where the biopsy came from. This part of the report may describe the size of the sample and the size and appearance of any lesion within it.

Sample pathology report

Patient name: SMITHSON, Mary
DOB/Sex: 1/01/1951, F
Requested by: Dr Jackson, Sally
Requested on: 01/05/2016
Specimen received: 02/05/2016

PATHOLOGY REPORT

CLINICAL DETAILS

Changing lesion, right back.

MACROSCOPIC

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

MICROSCOPIC REPORT

Specimen type: Excision
Site: Right back
Diagnosis: Melanoma
Classification/Main pattern: Nodular
Thickness: Breslow 2.6mm
Clark level: IV
Ulceration: Present
Dermal mitoses: 5 per mm^2

SUMMARY

Skin right back, excision, NODULAR MELANOMA

Diagnosis

Melanoma. This diagnosis will also usually be confirmed in the summary of the report.

Breslow thickness

This is the depth of your melanoma in millimeters and is used along with other features to stage the melanoma. Thinner melanomas have a better prognosis.

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

Clark level

Your pathology report may also show a Clark level. This is a number that ranges from I-V to describe how deeply the cancer has penetrated the skin. Clark level V is the deepest level of invasion. Clark levels are not to be confused with stages of melanoma.

If you have further questions, talk to your doctor.

Ulceration

Ulceration is the absence of the top layer of skin over the melanoma. The presence or absence of ulceration is used to help determine the stage of melanoma. The presence of ulceration indicates a faster growing melanoma.

Mitotic rate

This describes how quickly the melanoma cells are dividing. This is usually measured as number of mitoses per mm^2. Higher mitotic rates (e.g. greater than 5 per mm^2) indicate faster growing melanoma and are associated with a worse prognosis.

Surgical margin

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

Lymph node status

The number of lymph nodes removed at surgery and the number of nodes with melanoma cells present in them will be recorded on the report you receive after surgery.

Staging melanoma

Staging a melanoma provides a description of how widespread the cancer is.

Characteristics described in your pathology report (including Breslow thickness, ulceration, mitoses and the involvement of lymph nodes or other organs) determine the stage of your melanoma and guide your treatment approach.

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

In Australia, we use the American Joint Committee on Cancer (AJCC) system to stage a melanoma. This means three main pieces of information are looked at – tumour thickness (T), status of draining lymph nodes (N), and presence or absence of metastasis (M). This is referred to as TNM.

Stage	What does this mean?	Likely course of action
Stage 0 (In-situ)	At this stage the tumour 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. Also called in-situ melanoma.	Surgical removal (wide local excision) is the main treatment.

Stage	What does this mean?	Likely course of action
Stage I	A stage I melanoma can be up to 2mm in thickness without ulceration; or up to 1mm in thickness with ulceration.	Surgical removal with wide local excision is the main treatment. Sentinel node biopsy (removal of nearby lymph nodes) may be considered to rule out spread of melanoma to lymph nodes if your melanoma is greater than 1mm in Breslow thickness or in thinner melanomas with adverse prognostic factors (e.g. presence of ulceration or a high mitotic rate).
Stage II	Stage II melanoma is defined by thickness and ulceration. Tumours thicker than 2mm with or without ulceration, and tumours between 1–2mm with ulceration.	Surgical removal with wide local excision is the main treatment. Sentinel lymph node biopsy may be considered to look for spread of melanoma to local lymph nodes.
Stage III	Stage III melanoma is where the melanoma has spread to nearby or local lymph nodes or tissues. It can be of any thickness.	Surgical removal is the main treatment. Lymph node dissection (removal of all lymph nodes within the region concerned), drug and radiation therapies may be considered.
Stage IV	Stage IV melanoma can be any thickness with spread (metastases) to distant lymph nodes or to distant sites (e.g. lung, liver, brain, bone).	Surgery or systemic (drug) therapies including immunotherapy and targeted therapy may be recommended. Radiation therapy may also be used.

Prognosis

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

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

You may find it helpful to talk to a professional, such as a counsellor or psychologist, about your prognosis. You can read more about accessing this support on page 36.

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

Treatment

Surgery

A primary melanoma always requires surgical removal. This surgery is called a wide local excision. It involves removal of the melanoma or scar from the initial biopsy, along with some normal skin around it and some layers of tissue deeper than it, to check that all cancer cells are removed. If the wound is small it can usually be closed with stitches, staples or clips. Larger wounds may require a skin flap or skin graft at the time of surgery to close the wound created by removing the melanoma. The need for a skin flap or a skin graft will depend on the location and size of the tissue that is being removed.

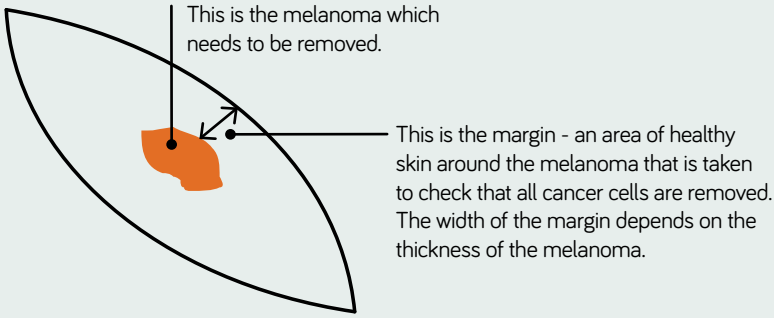
The wide local excision can be performed as a day procedure using local anaesthetic although some people will require a general anaesthetic or a hospital stay.

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

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

Wound care

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



Side effects from surgery

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

Scars

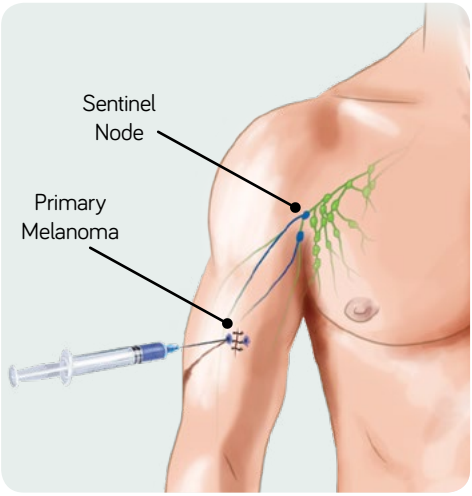
You will have a scar after your surgery. Everyone scars differently depending on skin type and how invasive the surgery was. Infections and wound complications can also alter the appearance of the scar. After surgery your scar will look red and raw, this will eventually settle and your scar will fade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

Sentinel lymph node biopsy

If your melanoma is of intermediate thickness (between 1mm and 4mm), or thicker (greater than 4mm) – or if your doctor thinks you have a fast growing or ulcerated melanoma - then a sentinel node biopsy may be discussed with you.

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

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



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.

The sentinel node is the first lymph node that drains lymph fluid from the particular area of skin that has melanoma. Sometimes there is more than one sentinel node.

A biopsy of the sentinel node involves mapping the nodes to find the first draining node (the sentinel node), and then surgically removing it. A pathologist examines this node to see if the melanoma has spread.

If your melanoma is thin (less than 1mm) then this procedure is usually not appropriate for you.

Patient Information Brochures

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

Adjuvant therapies

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

Radiotherapy following a lymph node removal is an example of how radiation can be used as an adjuvant therapy. Adjuvant therapy is not usually offered for treatment of Stage I or II melanoma but may be recommended in particular circumstances.

Radiotherapy

Radiotherapy uses radiation in the form of x-rays to kill cancer cells or to damage them so they do not multiply. Radiotherapy may also be used to control cancer growth or spread, or to relieve symptoms to make people more comfortable.

Clinical trials and research

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

Targeted therapies and immunotherapies

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

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

Understanding Radiotherapy

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

What is the role of complementary or alternative therapies?

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

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

Always discuss complementary or alternative therapies with those involved in your care.

Understanding Complementary Therapies

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

Massage and Cancer

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

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

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

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

When someone has had multiple melanomas or they have what is called Dysplastic Naevus Syndrome (more than one close family member who has had melanoma and many dysplastic or unusual looking moles) they may also be referred to a specialist centre.

What happens if the cancer comes back or spreads?

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

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

After treatment: what do I do now?

Follow-up

Attending follow-up appointments is a good way to monitor your health and to make sure that any concerns are dealt with quickly. Attentive follow-up care is important after treatment for any melanoma to monitor for recurrence and to check for other primary melanomas. Follow-up will involve a combination of physical examinations with your doctor and self examination.

Who will I see for follow-up?

Ask your doctor who is going to manage your follow-up care. Some people have a physical examination with their GP or dermatologist, others may see their surgeon. In some cases follow-up care is shared between two doctors.

How often should I attend follow-up?

Most recurrences of melanoma develop within the first five years after treatment, so your follow-up visits will be more frequent during this time. But late recurrence (even after 10 years) is also possible. How often your doctor will see you for follow-up visits depends on several factors, including the stage of the melanoma, your particular risk factors for recurrence and your general risk for developing other types of less worrying skin cancers such as basal cell carcinomas (BCC) and squamous cell carcinomas (SCC).

What will follow-up involve?

Your follow-up care will be guided by your melanoma history and any new or changing lesions that you or your doctor detect.

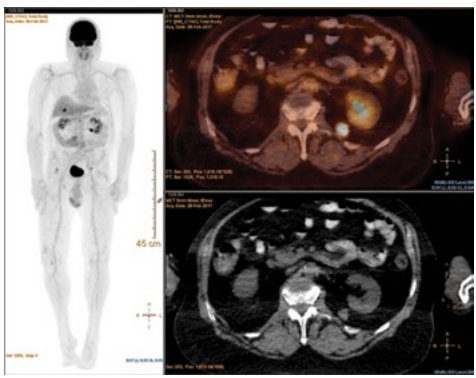
At each follow-up visit, your doctor will perform a thorough 'top to toe' physical examination – paying particular attention to the skin and lymph nodes – so that recurrence or a second primary melanoma can be detected early. This physical examination may be aided by the use of total body photography to detect any changes in your skin.

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

Your doctor will encourage you to participate in your follow-up care by examining your skin for potential melanoma. During these skin checks, you should also look for any abnormal lumps, especially where the surgery was done and in nearby lymph nodes. The 'ABCDE' rule on page 26 gives some information about what a melanoma commonly looks like.

What are the different types of scans?

Imaging or scans may be recommended as part of your follow-up. These scans use different methods to create an image of your insides. You may need to prepare for these scans by fasting (no food or drink), and you may be given an intravenous injection before the scan to help produce an informative image of what is going on. Please follow the instructions given to you by the imaging centre as each of these scans have different requirements.



- **Ultrasound** uses high frequency sound waves to look at internal structures. It is often used to look at smaller areas or specific organs of the body.
- **X-rays** use a form of electromagnetic radiation to create two dimensional images of the body.
- **CT (computerised tomography)** scans use x-rays to create an image of a cross section or very thin slice of the body. A CT shows the shape, size and location of lesions.
- **MRI (magnetic resonance imaging)** uses magnetic field and radio waves to produce images. An MRI is commonly used to look at joints, the brain and the spinal cord.
- **PET (positron emission tomography)** scans show how active cells are in the body. Sometimes PET and CT scans will be combined to give a more complete picture (as shown in the picture).
- **Bone scans** use a specialised camera to take pictures of your skeleton.

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

Self examination

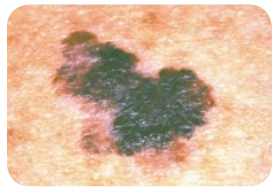
Being familiar with your skin will allow you to recognise changes early and act quickly. Your doctor will advise you on how often to check your skin.

What to look for

A

Asymmetry

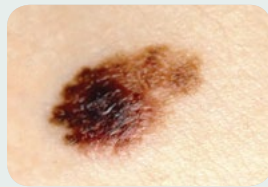
Watch for spots with an irregular **shape**. If you run an imaginary line through the middle, does one half of the spot look similar to the other?



B

Border

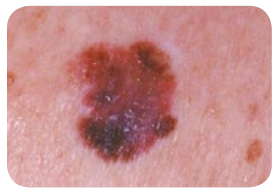
Watch for spots that have an irregular or ill-defined **border**.



C

Colour

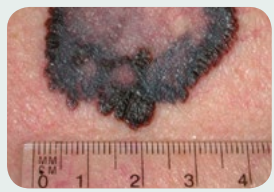
Look for **changing colours** or spots with more than one colour, including black, brown, red, blue, white and uneven or blotchy colours.



D

Diameter

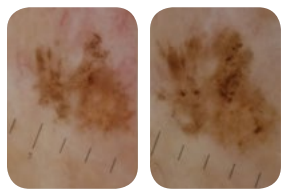
Take note of any increase in **size**, rapidly growing or particularly large spots.



E

Evolution

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



Some spots may not show any of the 'ABCDE' signs. For example, amelanotic melanoma is a type of melanoma containing less brown pigment. They are often harder to detect because they aren't discoloured like other melanomas. They can be normal skin colour, or pink, red or purple.

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

Where to look

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

Head, scalp, neck and ears
Use a hand-held mirror or ask someone to check areas you can't see easily.

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

Arms, hands, fingers and nails
Look carefully at forearms and upper arms.

Buttocks and legs
Check all sides from ankles to thighs.

Feet, including soles and toes
Be sure to check your nailbeds.

Don't forget to check around your excision site including your lymph nodes in that area as well as any new lumps.

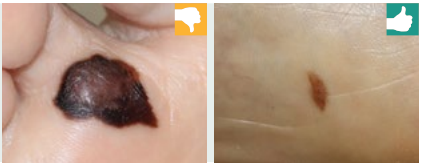
If you notice any of the signs described here, see your doctor as soon as possible.

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

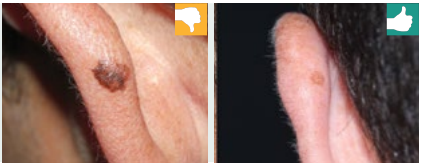
Get to know the difference between melanomas and benign moles or benign lesions by familiarising yourself with these photos. In each instance, the photos shown on the left are a melanoma or a concern.

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

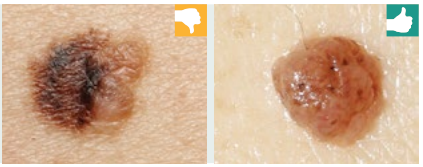
1.



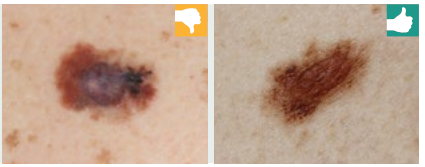
2.



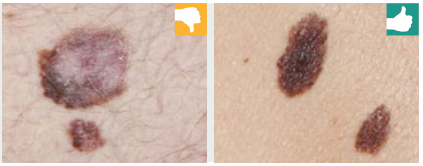
3.



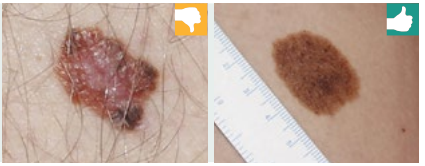
4.



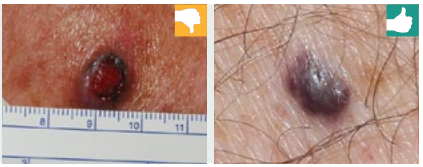
5.



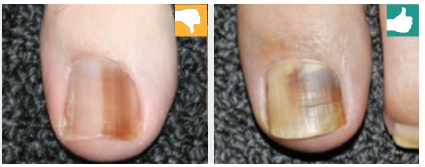
6.



7.



8.

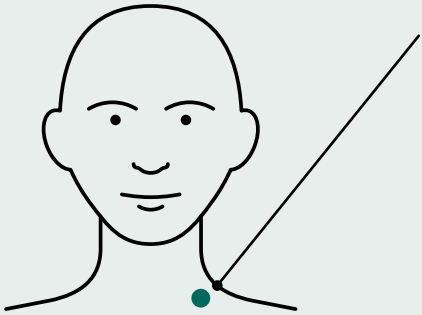


Squamous Cell Carcinomas and **Basal Cell Carcinomas** are other types of skin cancer. If you have had any type of skin cancer it is a good idea to examine your own skin and schedule a professional skin examination with your doctor.

Body maps

If you have moles or lesions you want to keep an eye on simply draw them on the body maps on pages 54 and 55 along with the date and any comments.

Example



1/01/2013 – new, 2mm, brown

4/01/2013 – checked by doctor

1/04/2013 – no change

1/07/2013 – changed: 3mm,
red spots, needs checking by doctor

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

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

Understanding your risk factors for melanoma

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

Anyone can get melanoma but these factors increase your risk:

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

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

Where do I get information if I have a family history of melanoma or would like to know more about genetic melanoma?

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

www.genetics.edu.au

www.genetics.edu.au/Publications-and-Resources/Genetics-Fact-Sheets/Genetics-Fact-Sheets

(go to factsheet 34)

Sun protection

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

Choosing sunscreen

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

Just like you may use a different face moisturiser for day and night, you can choose different types of sunscreen for different purposes.

If you are spending a small amount of time outside during a cooler part of the day, a sunscreen spray may be appropriate.

However, if you plan to be out in the sun for a prolonged period of time, you should choose a physical sunscreen – a cream that contains natural, mineral filters (titanium dioxide and zinc oxide) to reflect UV rays.

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

Applying sunscreen

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

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

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

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.

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

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

Wearing protective clothing

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

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

Vitamin D

What do I need to know about vitamin D?

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

Does sunscreen use prevent vitamin D production?

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

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

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

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

SunSmart

The SunSmart app shows the UV level for your location, provides a vitamin D tracker and a sunscreen calculator.

Notes

Keeping well during and after melanoma

Coping and emotional wellbeing

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

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

If you find that the way you feel is starting to interfere with the way you want to live your life, if you experience anxiety, stress or even depression, then it is important you talk to your medical 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 cope with your situation. Your medical team can link you to appropriate support and your GP can arrange Medicare cover for seeing a psychologist.

Living well after Cancer

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

Emotions and Cancer

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

A healthy lifestyle

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

Maintain your follow-up visits

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

Exercise

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

Exercise is Medicine Australia

www.exerciseismedicine.org.au/public

Find an accredited exercise physiologist at

www.essa.org.au

Rest

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

Diet

Having a good, nutritionally-balanced diet is important to maintain your energy and health. Fresh vegetables, fruit, nuts, lean meat, fish and non-processed food are a good start to a healthy diet. Discussing your diet with a dietitian can be helpful.

Dietitians Association of Australia

www.daa.asn.au

1800 812 942

Nutrition and Cancer

Resource available from Cancer Council

www.cancercouncil.com.au

13 11 20

Notes

Information and support resources

Written resources about melanoma

Understanding Melanoma

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

www.cancercouncil.com.au

13 11 20

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

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

www.melanomapatients.org.au

07 3721 1770

Websites

While the internet can be a helpful source of information it can also be overwhelming and inaccurate. Some useful websites that provide general melanoma information are listed here for your convenience, but always remember to discuss any information from the internet with those involved in your care.

Australian

Melanoma Institute Australia
www.melanoma.org.au

Cancer Council Australia
www.cancer.org.au

Melanoma Patients Australia
www.melanomapatients.org.au

International

Macmillan Cancer Support
www.macmillan.org.uk

US National Cancer Institute
www.cancer.gov

American Cancer Society
www.cancer.org

Myths about cancer

www.iheard.com.au

Support groups

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

Melanoma Institute Australia

www.melanoma.org.au

(02) 9911 7200

Melanoma Institute Australia support groups are run monthly in Melbourne and a range of NSW locations. Please see the website for details about a group near you.

Melanoma Patients Australia

www.melanomapatients.org.au

(07) 3721 1770

MPA groups meet on a regular basis in a range of locations throughout Australia. Phone MPA for details about a group near you.

melanomaWA

www.melanomawa.org.au

(08) 9322 1908

melanomaWA hold monthly meetings throughout Western Australia. Contact melanomaWA for more information.

Support is not the same for everyone

For some people the idea of seeking support can 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 need, whether it is financial, practical, emotional or informational. Many services are available in different forms; in-person, over the phone and online.

Telephone and online support

Cancer Council Australia

www.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

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

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.

Melanoma Patients Australia

www.melanomapatients.org.au

Support Help Line: 1300 88 44 50

Information and support for loved ones

Young people

Talking to kids about cancer

Booklet available from Cancer Council

www.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

www.canteen.org.au

1800 835 932

Carers

Caring for someone with cancer

Resource available from Cancer Council

www.cancercouncil.org.au

13 11 20

Carers Australia

www.carersaustralia.com.au

(02) 6122 9900

Young Carers

www.youngcarers.net.au

1800 242 636

Quick contacts

Support groups

Melanoma Institute Australia

www.melanoma.org.au

(02) 9911 7200

melanomaWA

www.melanomawa.org.au

(08) 9322 1908

Melanoma Patients Australia

www.melanomapatients.org.au

1300 88 44 50

Cancer Council Australia

www.cancer.org.au

13 11 20

ACT	www.actcancer.org
NSW	www.cancercouncil.com.au
NT	www.cancercouncilnt.com.au
QLD	www.cancerqld.org.au
SA	www.cancersa.org.au
TAS	www.cancertas.org.au
VIC	www.cancervic.org.au
WA	www.cancerwa.asn.au

Psychologists

Australian Psychological Society

www.psychology.org.au

APS find a psychology service

1800 333 497

CanTeen

www.canteen.org.au

1800 226 833

Lymphoedema

Australasian Lymphology Association

www.lymphoedema.org.au

(03) 9895 4486

Exercise

Exercise is Medicine Australia

www.exerciseismedicine.org.au/public

Find an accredited exercise physiologist at

www.essa.org.au

Nutrition

Dietitians Association of Australia

www.daa.asn.au

1800 812 942

Other useful websites

American Cancer Society

www.cancer.org

MD Anderson Cancer Center

www.mdanderson.org

MacMillan Cancer Support

www.macmillan.org.uk

Notes

My personal record

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 .....

Dr. who took the biopsy .....

Location/s on my body .....

Result .....

Level of invasion (Clark) .....

Ulceration ..... Yes/present ..... No/absent .....

Mitotic rate .....

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

Stage of melanoma .....

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

My treatment summary

1.

Date of wide excision .....

Dr. performing the wide excision .....

Flap or skin graft needed ☐ Yes ☐ No

Sentinel Node Biopsy needed ☐ Yes ☐ No

Sentinel Node Biopsy result ☐ Positive (Melanoma)
☐ Negative (No Melanoma)

Clear excision margins ☐ Yes ☐ No

2.

Further surgery

Date of surgery .....

Reason for procedure .....

Dr. performing procedure .....

3.

Adjuvant (additional) treatment

Date of treatment .....

Type of treatment .....

Reason for treatment .....

Dr. providing treatment .....

4.

Wound care

Suture removal or dressing change .....

Post surgical appointment .....

5.

Side effects experienced

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My follow-up plan

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

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

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

.....

.....

I will check my own skin every ☐ months

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

.....

.....

My notes or questions

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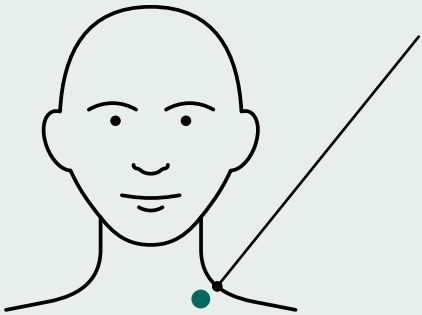
See pages 24–30 for more about skin examination and follow-up.

Body map

Use the body map on the next page to mark any moles or lesions that you want to keep an eye on over time. The image below provides an example of how you can monitor a mole over time.

Example



1/01/2013 – new, 2mm, brown

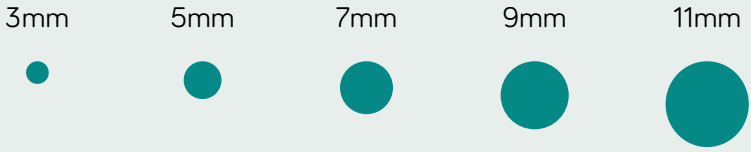
4/01/2013 – checked by doctor

1/04/2013 – no change

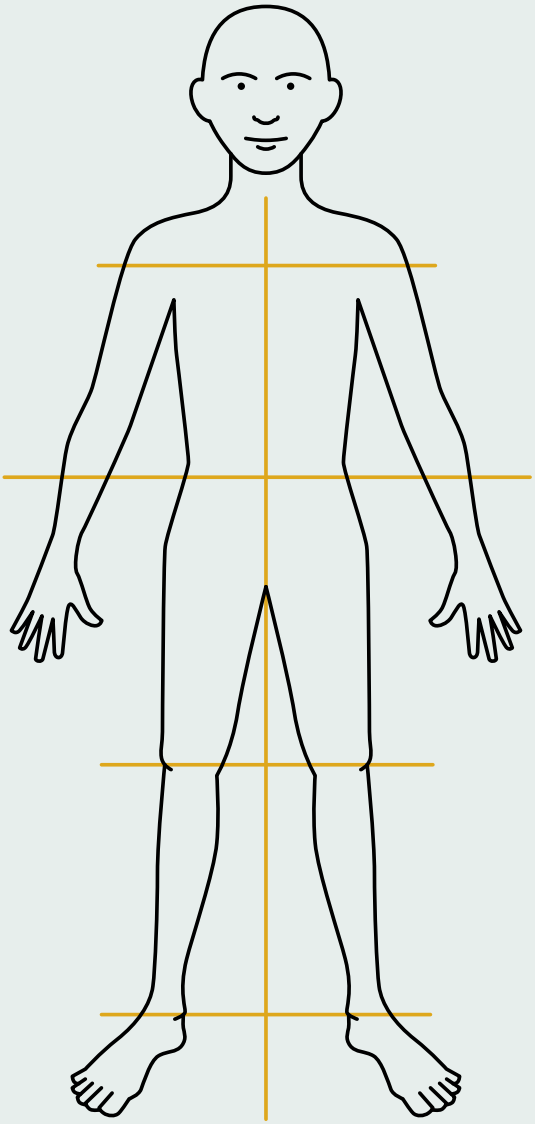
1/07/2013 – changed: 3mm,
red spots, needs checking by doctor

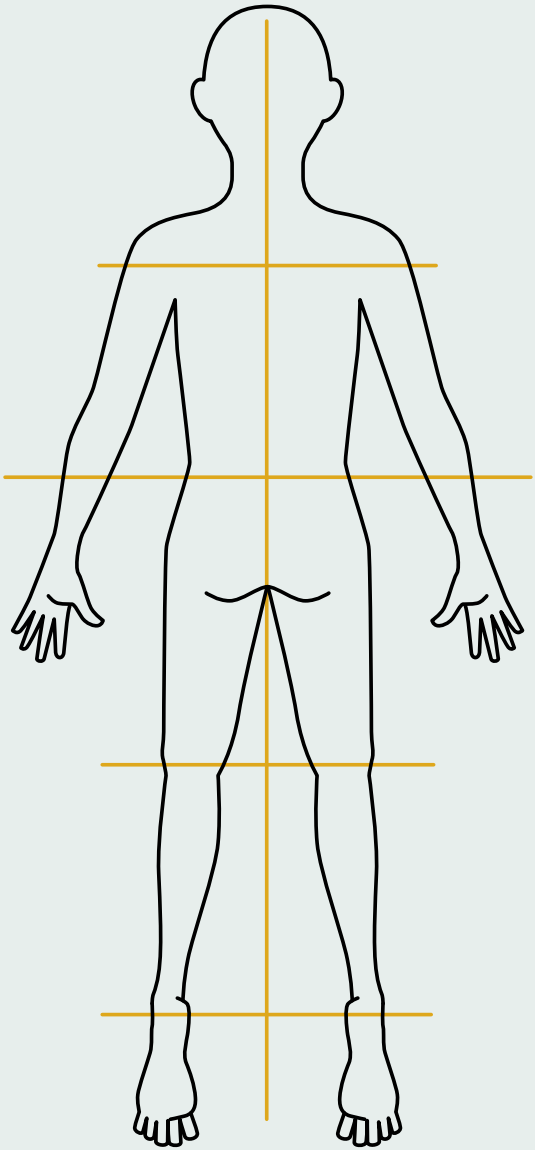
Use this size guide to measure the size of a mole or lesion that you are monitoring. Mark the size of the mole or lesion on your body map.

Size Guide



Body Map





My health professionals

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

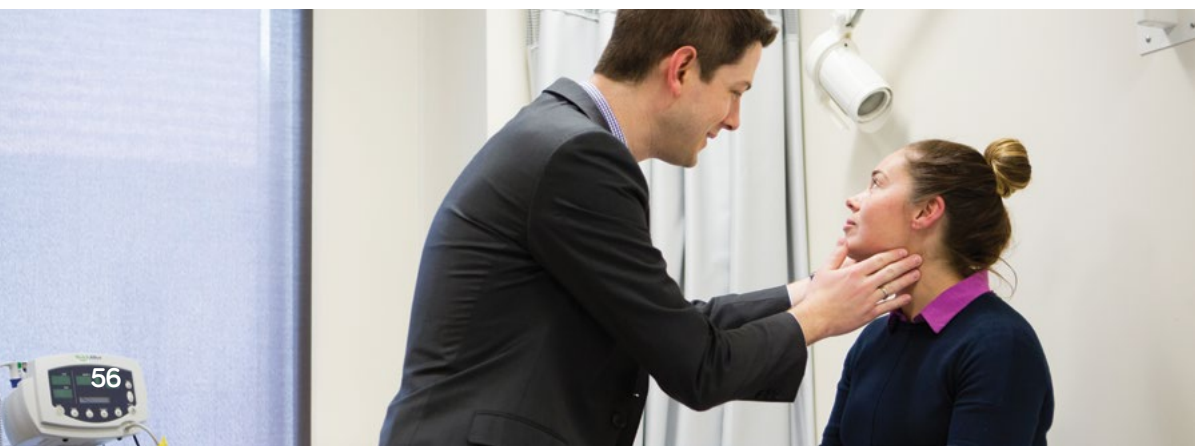
Health professionals you may see

General Practitioner
Manages your screening, diagnosis, general health needs and follow-up care. On some occasions, your GP may refer you to a specialist.

Dermatologist
A specialist in the diagnosis, treatment and prevention of skin disease and skin cancers.

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

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



Name .....

Occupation/Department .....

Phone .....

Email .....

Address .....

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

Notes .....

Name .....

Occupation/Department .....

Phone .....

Email .....

Address .....

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

Notes .....

Name .....

Occupation/Department .....

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

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Name .....

Occupation/Department .....

Phone .....

Email .....

Address .....

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

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 lower layer.

Epidermis

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

In-situ

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

Lesion

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

Malignant

Cancer.

Melanocytes

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

Melanoma

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

Metastatic melanoma

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

Nevus

Another term for mole, birthmark or beauty spot.

Prognosis

The likely outcome or course of a disease.

Recurrence

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

Sentinel node biopsy

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

Systemic therapy

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

Tumour

An abnormal growth of cells.

Ulceration

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

Wide local excision

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

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.

My appointments

Appointment with .....

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

Location .....

Reason for appointment .....

Notes: .....

.....

Appointment with .....

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

Location .....

Reason for appointment .....

Notes: .....

.....

Appointment with .....

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

Location .....

Reason for appointment .....

Notes: .....

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Appointment with .....

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

Location .....

Reason for appointment .....

Notes: .....

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Appointment with .....

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

Location .....

Reason for appointment .....

Notes: .....

.....

Appointment with .....

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

Location .....

Reason for appointment .....

Notes: .....

.....

Acknowledgements

This book was designed with the help of people who have experienced melanoma. The generosity of those diagnosed with melanoma and their families who shared their stories and gave their time and energy to this project is very much appreciated.

Many health professionals contributed content, ideas and provided valuable feedback about this project. These contributions are greatly appreciated.

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Neutrogena®

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