

There is no such thing as a 'silly' question. Asking questions and talking about your concerns is an important part of your melanoma care.

# Melanoma

QUESTIONS AND ANSWERS

In collaboration with



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#### **Note to readers**

Please always consult your doctor before beginning any health treatment. This booklet provides general information and should not be seen as a substitute for the advice of your doctor or other health professionals. However, you may wish to discuss issues raised in this booklet with your health care team. All care has been taken to ensure the information in this booklet is accurate at the time of publication.

#### **Contact details**

If you would like to speak to someone in relation to this booklet, please contact Melanoma Institute Australia on (02) 9911 7200 or [supportivecare@melanoma.org.au](mailto:supportivecare@melanoma.org.au).



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# Who is this booklet for?

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Have you been diagnosed with melanoma? Or perhaps a friend or family member has recently learned they have melanoma?

## What do you need to know?

You may have a number of different questions running through your mind. Some of the questions addressed in this booklet include:

- What is melanoma?
- Why did I develop melanoma?
- How can melanoma affect the way I feel?
- How can I cope with melanoma?
- How can I help someone who has melanoma?
- What tools can help me manage melanoma?

## What if I have advanced melanoma?

This booklet does not specifically deal with the challenges associated with advanced (stage III-IV) melanoma. Please see Melanoma Institute Australia's **Your Guide to Stage III Melanoma** and **Your Guide to Stage IV Melanoma** booklets for tailored information.

## Is this booklet based on the latest scientific research?

This booklet is based on the Australian Clinical Practice Guidelines for the Diagnosis and Management of Melanoma, Recommendations for the Identification and Management of Fear of Cancer Recurrence in Adult Cancer Survivors and Clinical Guidance for Responding to Suffering in Adults with Cancer. The recommendations in these guidelines and this booklet are based on extensive research. Throughout this booklet, we have also included thoughts and experiences that people with melanoma have shared with us over the years. These are indicated in **dark green & italics**.

## Using this booklet

This booklet is designed to complement the information in Melanoma Institute Australia's booklets called **Melanoma Prevention and Early Detection** and **Your Guide to Early Melanoma**. Please read these booklets for more information about:

- Melanoma prevention
- Melanoma diagnosis
- Treatments for melanoma
- Health outcomes (prognosis) after melanoma

For free copies of any of the Melanoma Institute Australia booklets mentioned on this page, call the Melanoma Institute Australia on **(02) 9911 7200** or visit: **[www.melanoma.org.au](http://www.melanoma.org.au)**

Sometimes it's hard to know what questions to ask. This booklet can help you to think about the things that are important to you.

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There is a lot of information in this booklet. You do not need to read all this information all at once, or from start to finish. You can dip in and out of the different sections depending on what you need and how you feel.

# 1 What is melanoma?

Melanoma is a type of skin cancer. It can occur anywhere on the skin, even on the soles of the feet.

Melanoma is named after the cells in our skin (called melanocytes) that produce the pigment that gives our skin its colour and that causes freckles and moles. Melanocytes also help to protect the body against the damaging effects of ultraviolet radiation. When our skin is exposed to the sun, melanocytes produce more pigment, causing the skin to darken or tan.

### What's happening at a cellular level?

Like all cells in our body, melanocytes normally grow and multiply in an orderly way (Figure 1). But if there is a problem with this process, our melanocytes can grow in an uncontrolled way (Figure 2). This uncontrolled growth may develop into a lump called a tumour.

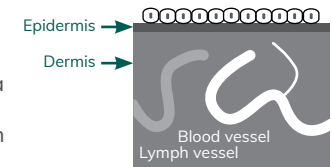


Figure 1. Normal cells

### Why is it called a malignant tumour?

While tumours can be benign (not cancer), in melanoma the tumour is malignant (cancer). A malignant tumour is made up of cells that grow out of control and sometimes spread to other parts of the body. Melanoma is the least common but most serious type of skin cancer because it can grow quickly and spread.

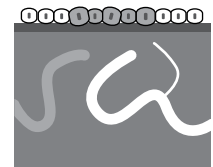


Figure 2. Abnormal cells

### Melanoma are categorised according to their depth:

#### Melanoma in situ

Melanoma in situ is the earliest stage of melanoma. 'In situ' means that the melanoma cells have only developed on the outer most layer of the skin (the epidermis) (Figure 3). Because melanoma in situ is contained only on the surface of the skin, it does not spread to other parts of the body. Prognosis for melanoma in situ is excellent.

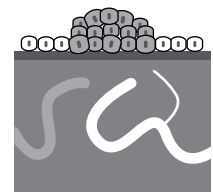


Figure 3. Abnormal cells multiply

#### Invasive melanoma

Invasive melanomas are those which have invaded (or grown) beyond the epidermal layer of the skin into the next layer (the dermis) (Figure 4). As a result there is potential for the melanoma to spread to other parts of the body. The deeper the invasive melanoma has grown, the greater the chance of spreading to other parts of the body (Figure 5). Invasive melanomas may be thin (1mm or less), intermediate (between 1mm and 4mm) or thick (greater than 4mm). Fortunately, in most cases, melanoma does not spread to other parts of the body and the prognosis is good.

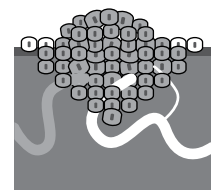


Figure 4. Invasive melanoma

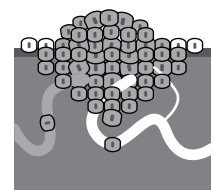


Figure 5. Melanoma spread

# What are the different types of melanoma?

Melanomas are categorised by their clinical and pathological appearance. About 90% of melanomas appear as a darker colour but about 10% appear as pink or red (amelanotic melanoma). The most common 4 types of primary cutaneous melanoma include superficial spreading melanoma, nodular melanoma, lentigo maligna & lentigo maligna melanoma, and acral lentiginous melanoma. Other, less common types of melanoma include desmoplastic, mucosal and intraocular.



Amelanotic melanoma

Superficial spreading melanoma

Nodular melanoma



Lentigo maligna & Lentigo maligna melanoma

Acral Lentiginous melanoma

Desmoplastic melanoma

These less common types of melanoma can be more difficult to detect. Please refer to the Melanoma Institute Australia **Melanoma Prevention and Early Detection** and **Your Guide to Early Melanoma** booklets for more information on the features of these different types of melanoma.

Melanoma can develop anywhere on the skin. If you notice a mole that changes, itches, bleeds or seems different from the others (even if it is small or new), see your GP or dermatologist.

# How is melanoma diagnosed?

If your doctor suspects a melanoma, the lesion of concern may be removed. This is called an excision biopsy and is normally a quick and simple procedure that may be done by your GP, dermatologist, or a surgeon.

For an excision biopsy:

Local anaesthetic is injected into the area near the mole.

The doctor then uses an instrument called a scalpel to remove the spot and a small area of tissue around it.

Stitches are then used to close up the wound.

The removed skin is sent to a pathologist, who looks at it under a microscope in a laboratory.

Results are usually ready within 10 days, at about the time the stitches may need to be taken out.

This waiting period is normal but it is often an anxious time for patients. During this time, try not to let your mind run away with itself. Keep in mind that the health outcomes for melanoma are excellent when it is detected and treated early.

If the pathologist thinks that it is a melanoma, further surgery is needed so that a larger section of skin is removed from the same place. This is known as a wide excision and the size is decided by the thickness of the melanoma.

## What melanoma features are important when deciding on treatment?

As well as the type of melanoma, your doctor will consider the following features when making decisions about your treatment:

- Breslow thickness
- Ulceration
- Surgical margins
- Mitotic rate

The glossary at the back of this booklet describes each of these medical terms.

## What is a sentinel node biopsy?

Sometimes melanoma can travel through the lymph vessels to other parts of the body. When this happens your lymph nodes may become swollen. Lymph nodes may also become swollen for other reasons such as infections. If your doctor is concerned about an enlarged lymph node, he or she may perform an ultrasound, take a sample of cells using a fine needle, or you might have a sentinel node biopsy.

A sentinel node biopsy uses a special dye to see if the melanoma has spread to the draining lymph nodes. The doctor will use this information to diagnose the stage of melanoma, and this will help you and your health care team decide which treatments are most suitable for you.

**Keep in mind that the health outcomes for melanoma are excellent when it is detected and treated early.**

## How does melanoma spread?

Sometimes melanoma cells can spread to other parts of the body by travelling through the bloodstream or lymphatic system. When these cells reach a new place in the body they may continue to grow and form another tumour. This is called a metastasis.

### How common is metastatic melanoma

Overall, metastatic melanoma is not common, with doctors taking into account multiple factors when assessing your personal risk. For information about your risk of metastasis, please speak to your treating doctor.



Most melanomas (up to 98%) are diagnosed before they have had a chance to spread to other areas of the body. Treatment for these early-detected melanomas is highly effective. This is why early detection of melanoma is so important.

## What are the treatments for melanoma?

Although melanoma is the most serious type of skin cancer, it can be treated successfully if caught early.

### How do I know which treatment is best for me?

After you have been diagnosed with melanoma, your health care team will discuss the best treatment for you based on your melanoma features and other factors, such as your age and general health. The most common treatment for melanoma is removing the melanoma with surgery. For most cases of early stage melanoma, this is the only treatment required.

Metastatic (advanced) melanoma may also require treatments such as immunotherapy, targeted therapy or radiotherapy. You may have one of these treatments or a combination.

Treatments for advanced melanoma are improving all the time and finding better treatments is a major focus of melanoma research. Your doctor will advise you on the best treatment for your particular melanoma. Your doctor may also suggest you consider taking part in a clinical trial. A clinical trial is research testing the safety and effectiveness of new treatments.

For more information about melanoma treatments, visit the Melanoma Institute Australia website: [www.melanoma.org.au](http://www.melanoma.org.au)

### Waiting for test results and for treatment to begin can be difficult.

During this time you may be learning more about your melanoma, the treatment and possible side effects, and this can help you in making decisions.

You may also find it helpful to use some of the strategies in this booklet or to talk to different people including:

- Your health care team
- Your family and friends
- Other people who have had similar experiences

There is no such thing as a 'silly' question. Asking questions and talking about your concerns is an important part of your care.

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## Why did I develop melanoma?

Australia has the highest incidence of melanoma in the world. More than 14,500 Australians are diagnosed with melanoma each year and it is the most common cancer in young people aged 15 to 39 years.

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### How common is melanoma?

#### **Melanoma affects more men than women**

About 7 in every 100 men and about 5 in every 100 women will develop melanoma by the time they reach the age of 85. This is the average risk of developing melanoma in Australia. If you would like personalised information on your risk of melanoma, please speak to your treating doctor.



## What increases my risk of melanoma?

While we know that some groups of people are at higher risk of melanoma than others, we cannot tell exactly who will develop melanoma. Understanding the factors that contribute to your risk is an important step towards reducing your risk of developing further melanomas.

While anyone can develop melanoma, there are certain factors that can increase your risk. These include: being male, sun exposure, using sunbeds, having many moles, a previous melanoma, fair skin, previous non-melanoma skin cancer, skin damage from the sun, a family history of melanoma, or older age.

## Exposure to Ultraviolet (UV) radiation from the sun or sunbeds

A common cause of melanoma is exposure to UV radiation, either from the sun or from other sources such as a solarium tanning machine. Sunburn, lots of holiday, weekend, sporting, recreational or occupational sun exposure, and using a solarium tanning machine all increase the risk of developing melanoma. The risk is higher when exposure to these sources of UV radiation occurs during childhood and adolescence, but sun exposure at all ages is a factor. Remember, it is never too late to improve your sun protection.

## Moles

### What are moles?

Moles are harmless growths of pigment cells (melanocytes) in the skin. Almost everyone has moles and they appear on our body in our first 40 years of life. Moles can be flat or raised and can differ greatly in colour, size and shape. Most moles develop as a result of our genetics, although sun exposure (especially during childhood) also contributes to mole development.

Normal moles can change as you get older. They often slowly become dome-shaped with age and lose their colour. Only rarely do moles change to melanoma.

### Should I have all my moles removed to prevent melanoma?

No. The removal of normal moles does not prevent melanoma. There is also an increased risk of scarring and other complications with mole removal.

### Do all melanomas start as moles?

Less than half of melanomas arise from existing moles; most melanomas are new growths.

### Does the number of moles I have matter?

One of the most important risk factors for melanoma is having a lot of moles. The average mole count is between 10 and 40 moles on the body. The more moles you have, the greater your risk of developing melanoma. People with more than 100 moles are at higher risk of melanoma.

### Do I need to check my moles regularly?

While most moles will never become malignant, people with dysplastic moles (see glossary, page 63) do have an increased risk of developing melanoma. People with dysplastic naevus syndrome, as well as a personal or family history of melanoma, are at particularly high risk of developing melanoma.

Because of the increased risk associated with dysplastic naevus syndrome, a personal or family history of melanoma, it is important to have your skin examined by a doctor at recommended intervals.

## Previous melanomas

### What if I've had previous melanomas?

Having a previous melanoma means you are more likely to develop another melanoma.



### In a group of 100 Australians...

13 who have had ONE previous melanoma, 13 will develop a second melanoma within 10 years

If you have had more than one previous melanoma, please speak to your treating doctor for information on your personal risk of developing another melanoma.

To detect melanoma early, it is important to look for changes everywhere on your skin, as well as for changes in spots or moles. See pages 19-20 of this booklet for tools to help you check your skin.



### Previous non-melanoma skin cancer or skin damage

A person who has had a non-melanoma skin cancer or skin damage from the sun is at increased risk of developing melanoma. Non-melanoma skin cancers include basal cell carcinoma (BCC) and squamous cell carcinoma (SCC). Other signs of skin damage caused by the sun include having actinic keratoses, solar lentigos, or solar elastosis. The glossary at the back of this booklet describes each of these skin conditions.

### Fair skin

Melanoma is more common in people with fair skin that tends to burn or freckle easily. This is because fair skin has less natural protection from UV radiation compared to darker skin. Having naturally darker skin lowers your risk of melanoma, but it does not eliminate your risk.

### Age

Like most cancers, the risk of developing melanoma increases with age. Melanoma is most common in people aged over 50. While younger people are less likely to get cancer, in those that do, melanoma is the most commonly diagnosed cancer for people aged between 15 and 39.

### Family history

In Australia, melanoma is a common disease. This means that many people have someone in their family who has had melanoma. In most families, this is due to chance or other factors such as having similar patterns of sun exposure. However, in a small proportion of people with melanoma there may be underlying inherited factors that contribute to the development of melanoma.

## How do genetic factors influence melanoma risk?

Researchers have found a few genes where specific, permanent variations (also referred to as a 'mutation' or 'faulty gene') can be inherited (or passed on) in families and can strongly increase melanoma risk.

“ They tend to say melanoma is caused by excessive exposure to sunlight but I've never been a sun person, never ever. So to have had two melanomas, it doesn't make sense for it to just be a sun-related illness. ”

The most well-known of these genes is called CDKN2A. This gene produces a protein (called p16) which plays an important role in controlling the growth of cells.

About 2% of people with melanoma have inherited a variation in the CDKN2A gene which substantially increases their risk of melanoma. Thus, having a strong inherited risk of melanoma is rare.

### Signs that melanoma could be due to a strong inherited genetic risk include:

Having three relatives in the family with melanoma.

Having more than one melanoma diagnosed in the one person.

Melanoma diagnosed in a person younger than 40.

If you have a family history of melanoma it is important to share this information with your health care team, including your GP.

### Are there other genetic factors that can influence melanoma risk?

Researchers have also found that variations in several other genes can increase melanoma risk by affecting a person's skin colour, moliness, or sensitivity to the sun.

While these genetic variations are also inherited, they do not increase melanoma risk as strongly as CDKN2A mutations do. However, it is possible that combinations of these weaker genetic variations may also cause a family history of melanoma, several early stage melanomas in the one person, or melanoma at a young age.



#### In any group of 100 people in Australia with melanoma...

- 78 to 88 are unlikely to have inherited an increased risk of melanoma
- 10 to 20 people will have weaker genetic variations that increase their risk of melanoma
- 1 or 2 people will have a strong inherited risk of melanoma

For more information about melanoma and genetics, you can call the Cancer Council Information and Support Service on **13 11 20**. You can also visit the Centre for Genetics Education website: [www.genetics.edu.au](http://www.genetics.edu.au). Here you will find a fact sheet on melanoma.



## How can I learn more about my family history of melanoma?

In families where several relatives have had melanoma, it may be helpful to consider seeking advice from a family cancer service.

### What is genetic counselling for melanoma risk?

For some families, genetic counselling through a professional and accredited family cancer service can help each family member to:

- Have a better understanding of their risk of melanoma based on their family history
- Know which medical check-ups are appropriate
- Explore the possibility of genetic testing for melanoma risk
- Be aware of the potential limitations, benefits and disadvantages of genetic testing for melanoma risk

Genetic testing for variations in the genes associated with melanoma is complex and is not widely available in Australia. Your doctor is the best person to talk with about the options that may be available.

# 3 Practical information and helpful tools I can use

## Skin self-examination

More than half of all melanomas are first discovered by the patient. This highlights the importance of knowing your skin and making sure you see a doctor if you are worried or something has changed.

### What do I need to look for?

When checking your skin for changes, you should look out for moles or spots with **any** of the following characteristics:

#### A Asymmetry

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



#### B Border irregularity

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



#### C Colour variation

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



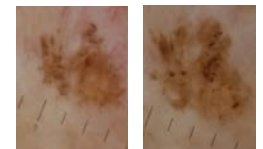
#### D Diameter

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



#### E Evolution

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



### Normal moles do change as you get older

As you get older, your skin changes and you may notice that some of your moles slowly lose their colour or become more dome-shaped. Knowing how to distinguish these normal changes from melanoma can be difficult. If in doubt, ask your doctor to check your skin.

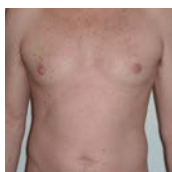
### Where can I learn more about skin self-examination?

The Cancer Council's SunSmart website gives tips for checking your skin and includes an online video showing a step-by-step approach to skin self-examination:  
[www.sunsmart.com.au/skin-cancer/checking-for-skin-cancer](http://www.sunsmart.com.au/skin-cancer/checking-for-skin-cancer)

## How should I check my skin?

This tool is designed to help you carefully examine your skin every three months for new spots or moles, or changes in existing moles.

**Remember:** Good light will help you to see your skin well. It is also helpful to use a mirror or to have another person check areas that are hard for you to see, such as your back and scalp. You can also ask your hairdresser to check your scalp when you have your hair cut.



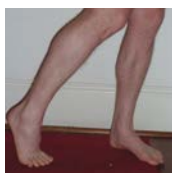
### Check the front of your body.

Then check your right and left sides with your arms raised.



### Look carefully at your arms.

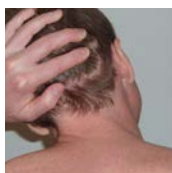
Then check the front and back of your upper arms and hands.



### Check your legs, feet and toes.

Look at the front and back of your legs and feet, as well as the spaces between your toes.

Don't forget to check the soles of your feet.



### Use a hand mirror.

Check the back of your neck and your scalp with a hand mirror. When checking your scalp, part and lift your hair so you can see your skin.



### Finally, check your back and buttocks.

## How does my doctor monitor my skin and moles?



Dermatoscope



Total body photography

Doctors use a number of tools and techniques to check your skin, beyond what the naked eye can see. These include dermoscopy using a dermatoscope (Photo 1), digital monitoring, and total body photography (Photo 2). These tools help reduce unnecessary biopsies and detect melanomas at an early stage.

A dermatoscope is a magnifying lens with a special light. Digital monitoring involves taking a magnified photo of a mole or an area of your skin and storing it on a computer. You are usually asked to return to see the doctor after 3 or 6 months so that a new photo can be taken and compared to the previous one. This can help your doctor to see whether the skin or mole is changing over time.

Sometimes doctors will take photos of the skin all over your body. This is known as total body photography. This is particularly useful for people who have many moles. Although most close up photos of your moles are stored electronically by your doctor, if you do have physical copies of these photos it may be helpful for you to keep them with this booklet and use the information on page 19 and the guide on page 20 when checking your skin.

More information on these tools and techniques is available from the Melanoma Institute Australia website: [www.melanoma.org.au](http://www.melanoma.org.au).

## Should my children and other family members also have skin checks?

Melanoma is rare before puberty. For this reason, younger children usually only have their skin examined by a doctor if their parent is concerned about a particular spot or mole. While teenagers can develop melanoma, their risk is much lower than adults. Regular skin checks by a doctor in adolescence would usually only occur when other risk factors are present, such as a known genetic cause of melanoma in the family. If you have been diagnosed with melanoma, your relatives should discuss with their doctor whether or not ongoing skin checks are recommended for them.

## What is the role of vitamin D?

Ultraviolet (UV) radiation from the sun is one of the main causes of melanoma, but it is also one of the best sources of vitamin D. In Australia we need to balance the need for sun protection with our body's need for vitamin D.

### What is vitamin D and why is it important?

Even if you have had melanoma, some sun exposure is still important because it allows your body to make vitamin D, which is essential for good bone health and may have other health benefits. Small amounts of vitamin D can also be found in foods such as oily fish (salmon, herring and mackerel), liver, eggs and some dairy products.

### How much sun do I need to maintain adequate vitamin D levels?

The amount of sun exposure needed for adequate vitamin D levels depends on:

**Age:** the older you are, the more sun you need.

**Skin type:** the fairer your skin, the less sun you need.

**Season:** the warmer the month, the less sun you need.

**Cloud cover:** the cloudier it is, the more sun you need. But remember, you can still burn on a cloudy day!

For people with fair skin, who tend to burn rather than tan, the amount of sun needed to maintain a healthy level of vitamin D differs depending on where in Australia you live.

In most areas of Australia you need: **6 to 8 minutes of direct sunlight a day before 10am or after 2pm**

In southern parts of Australia during winter you need: **30 to 50 minutes of direct sunlight a day before 10am or after 2pm**

Most Australians get all the sun they need from everyday outdoor activities such as walking to the local shops, waiting for a bus, hanging out the washing, or walking their children to school.

People who may be at risk of not having enough vitamin D for good health include:

- Those who are house-bound (particularly people who are very old or frail)
- Naturally dark-skinned people
- Those who cover their skin for religious or cultural reasons
- Those with a weakened immune system (including organ transplant recipients)
- People with osteoporosis

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

**Talk to your doctor if you are concerned about your vitamin D levels.** It may be necessary to measure the current level of vitamin D in your blood. People who do not get enough vitamin D from the sun or from their diet may need to take vitamin D tablets. Tablets should only be taken after discussion with your doctor.

## Sun protection after melanoma diagnosis

UV INDEX	
11+	EXTREME
8, 9, 10	VERY HIGH
6, 7	HIGH
3, 4, 5	MODERATE
1, 2	LOW

### The UV Index:

- Is higher in summer than in winter
- Is higher in the north than the south of Australia
- Can be high even on cool and overcast days

You can't rely on clear skies or hot weather to determine when you need to protect yourself from the sun.

In the northern states of Australia, sun protection is needed all year around at certain times of the day. In these areas, it is safe to go outside without sun protection in the early morning and late afternoon when the UV Index is below 3.

People in southern states may not need sun protection in winter when the UV Index is likely to be below 3. However, sun protection is always needed at high altitudes or near highly reflective surfaces like snow or water.

### When do I need sun protection?

The UV Index is a simple way of describing the intensity of UV radiation from the sun at different times of the day. The higher the UV Index, the greater the potential for damage to your skin.

Most people in Australia need sun protection when the UV Index is 3 or above. The UV Index is shown in the SunSmart app or on the Bureau of Meteorology website: [www.bom.gov.au](http://www.bom.gov.au) (search for UV alert).

### Download the App!

The Cancer Council SunSmart mobile phone App is free and contains useful information for any location in Australia. The App includes information about the times each day when you should use sun protection, as well as personalised alerts to remind you when sun protection is needed.

The App also includes a vitamin D tracker to help you find out if you are getting enough sun exposure for vitamin D, and a sunscreen calculator to help you work out if you are using enough sunscreen. This App can be downloaded from the app store or [www.sunsmart.com.au/resources/sunsmart-app](http://www.sunsmart.com.au/resources/sunsmart-app)



## How should I protect my skin from the sun?

It is never too late to improve your sun protection. Even if you have had a melanoma, good sun protection can reduce your risk. When in the sun and the UV Index is 3 or above, or if you are outside for long periods of time, or if you have very fair skin, it is important to remember to protect yourself in 5 ways:



Seek shade, especially in the hottest part of the day



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



Wear a broad-brimmed hat



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



Wear wrap-around sunglasses

## Which health professionals will be involved in my care?

It is important to have a General Practitioner (GP) to coordinate your care on an ongoing basis. If you have any concerns about your health, including with your skin, talking with your GP is a good place to start. Some GPs have extra experience and training in skin cancer diagnosis and treatment, and may undertake skin checks and skin cancer treatment, as appropriate. Your GP may also seek the assistance of the following specialists in your care:

### Dermatologist

A doctor who specialises in the diagnosis, medical and surgical treatment of skin diseases, including melanoma.

### General surgeon

A doctor who specialises in general surgery who may also remove skin cancers, including melanoma.

### Plastic surgeon

A doctor who specialises in skin surgery and performs operations to remove skin cancers, including melanoma.

### Pathologist

A doctor who specialises in the examination of skin and body tissue with a microscope in a laboratory to diagnose diseases, including melanoma.

### Melanoma nurse

A nurse who has extra training in assisting you through all stages of your melanoma diagnosis and treatment.

### Psychologist

A health professional who specialises in the diagnosis and treatment of psychological difficulties, and provides emotional care and support during times of stress.

### Social worker

A health professional who can help connect you with local support services and can assist with practical, emotional, and financial difficulties.

**Most people with melanoma will only need to have surgery to remove the melanoma. However, sometimes the following health professionals may also be involved in your care:**

### Medical oncologist

A doctor who specialises in the treatment of cancer with medications.

### Radiation oncologist

A doctor who specialises in the treatment of cancer with radiotherapy.



## What questions could I ask my doctor?

### It can be difficult to know what questions to ask.

The stress of learning that you have melanoma often makes it difficult to think clearly and to take in new information. You may hear what your doctor is saying, but you may find it difficult to remember this information once you have left his or her office. On the flip side, you may have lots of questions but in the heat of the moment it can be easy to forget what you want to ask.

### It's always okay to ask your doctor to repeat or clarify information.

We have developed a list of questions to help you think about the information that's important to you and the questions you may want to ask. There are a lot of questions listed below – don't feel you need to ask them all. You can always refer back to this section from time to time or as your situation changes.

Take this booklet along with you to your next appointment. This way you can note your doctor's responses in the space provided, for easy reference later on.

## My diagnosis

What type of melanoma do I have? \_\_\_\_\_

What stage is my melanoma? What does this mean? \_\_\_\_\_

Can you explain my pathology report to me? \_\_\_\_\_

Has the melanoma spread to my lymph nodes or another part of my body? \_\_\_\_\_

Was a lymph node biopsy done? Were any nodes positive? Were any nodes removed? \_\_\_\_\_

What treatment do you recommend? \_\_\_\_\_

Can you explain what dysplastic naevi are? Do I have dysplastic naevus syndrome? \_\_\_\_\_

What can I do if I have more questions after I leave today? \_\_\_\_\_

## My prognosis

What does this melanoma diagnosis mean for my future health? \_\_\_\_\_

What is the best case scenario? What is the worst case scenario? \_\_\_\_\_

What is the expected survival for people with my type and stage of melanoma? \_\_\_\_\_

How likely is it that the melanoma will come back? \_\_\_\_\_



How likely is it that the melanoma will metastasise or spread to other parts of my body? \_\_\_\_\_

Can you explain how a melanoma spreads? \_\_\_\_\_

How will melanoma affect my quality of life? \_\_\_\_\_

## My care

Do you work in a multidisciplinary team and who is part of my health care team? \_\_\_\_\_

Will you be in charge of my care? \_\_\_\_\_

How will the different clinicians involved in my care communicate with each other and with me? \_\_\_\_\_

## Costs

What costs will be involved throughout my care (e.g. medication, surgery costs)? \_\_\_\_\_

Who can I talk to if I am concerned about the financial costs involved in my care? \_\_\_\_\_

## Ongoing care and follow-up

How can I try to prevent this from happening again? \_\_\_\_\_

I have been told to check my own skin regularly. Can you show me how to do this correctly? Can you describe what I need to look for? \_\_\_\_\_

How often should I check my skin for changes? \_\_\_\_\_

What is my care plan? Will I continue to see you? \_\_\_\_\_

How much sun exposure is safe for me? \_\_\_\_\_

If I stay out of the sun, should I take a vitamin D supplement? \_\_\_\_\_

Could another melanoma develop and become dangerous in the time between my appointments? \_\_\_\_\_

If I notice a change in my skin, can I ask for an earlier appointment? \_\_\_\_\_

Where can my family go to have their skin checked? \_\_\_\_\_

## Information and support

What information is available about my melanoma and its treatment? Are there websites or books you could recommend for me? \_\_\_\_\_

Is there any information that can help me to explain what is happening to my family and friends? \_\_\_\_\_

Can I talk to someone who has been through this before? \_\_\_\_\_

Is it normal to feel worried or anxious? \_\_\_\_\_

Can I see someone to help me cope with how I'm feeling? What types of support services are available? \_\_\_\_\_

## If another melanoma develops

Is this a recurrence or a new melanoma? What is the difference? \_\_\_\_\_

Does this change any of the information I've been given before, such as my prognosis, my risk of developing another melanoma or my treatment options? \_\_\_\_\_

Have there been any advances in research and treatment options since my last diagnosis? \_\_\_\_\_

Does this mean I have a genetic susceptibility to melanoma? \_\_\_\_\_

Are my family members at risk of developing melanoma? \_\_\_\_\_

Would genetic counselling be helpful in my situation? \_\_\_\_\_

Comments: \_\_\_\_\_

## 4

# How can melanoma affect the way I feel?

Learning that you or someone you care about has melanoma can be unexpected, frightening and stressful. Following a diagnosis of melanoma, people can experience a range of feelings such as shock, fear, anger, sadness, disbelief or a combination of these emotions.

## How can melanoma affect the way I feel?

The way you think and feel about melanoma can change a lot over time. Throughout this process, your emotional care is just as important as your physical care.

“When the doctor said, ‘You’ve got melanoma’... bang! That sort of hit below the belt and it was panic stations for a couple of days. I was totally freaked out – completely and utterly shocked.”

Some people say their emotions are strongest when their treatment is over and they have had a chance to reflect on what has happened.

“You can’t go through something like that without being changed a little bit. A couple of people have told me I’ve changed, not for the better or worse, just changed.”

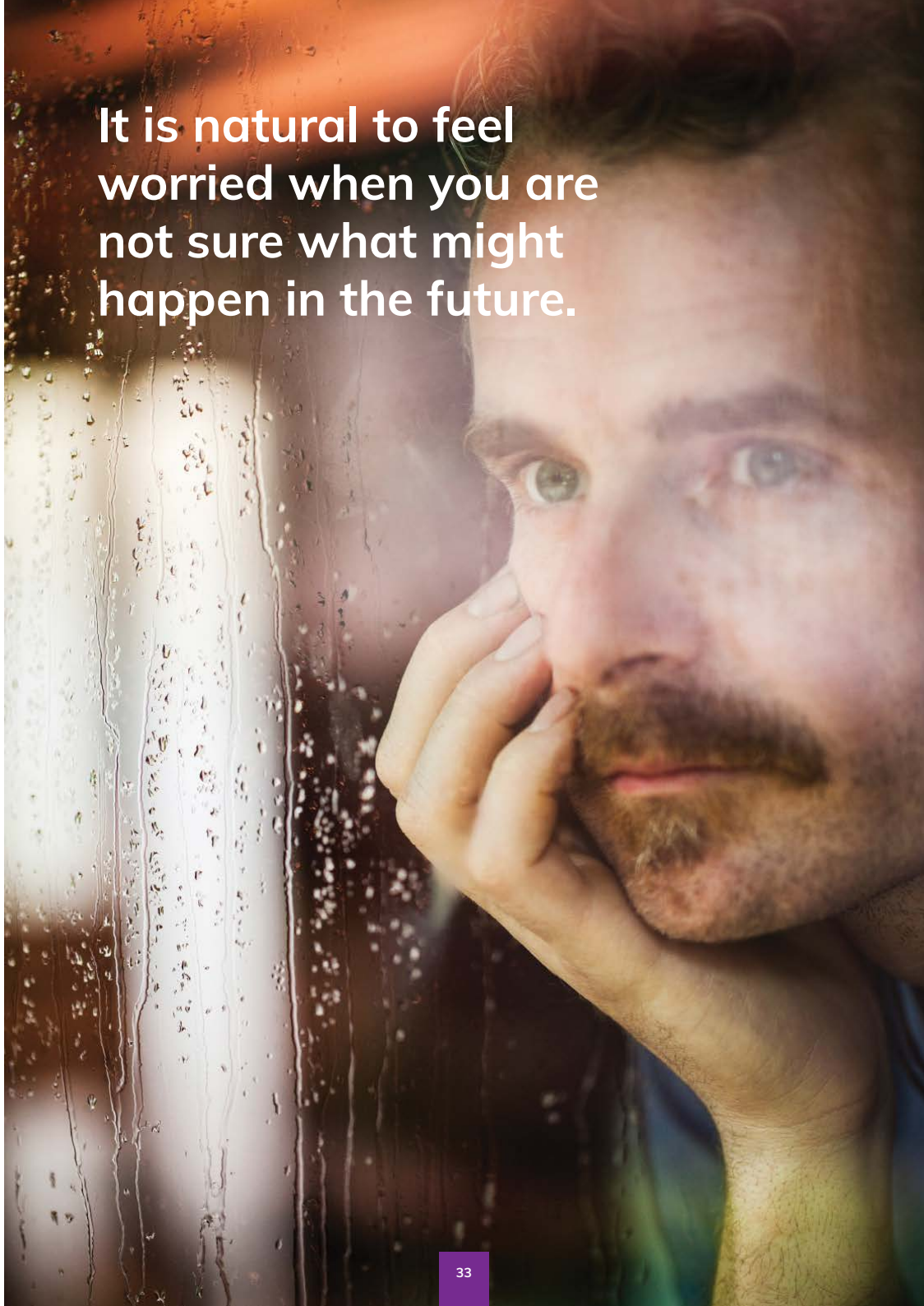
### Being diagnosed with melanoma can affect people in different ways.

Not everyone feels the same about the diagnosis and treatment of melanoma. Many people find it difficult to talk about their thoughts and feelings. Some people avoid talking about their emotions or seeking help because they think they should be able to cope on their own or because they don’t want to be a burden to others. Other people are encouraged by those around them to be strong and positive, which can make it harder to ask for help.

“I don’t think I’ve had any support. I don’t even go to things like the cancer afternoon teas.”

Being diagnosed with melanoma can affect your life in many ways, not just in terms of your physical health. Practical challenges such as the costs of treatment, ongoing care and travel to appointments can take their toll on you and your family. Concerns about these issues can affect how you are feeling, especially if they interrupt your daily activities.

On the next few pages, different feelings and experiences you may have after a melanoma diagnosis, and some ways of coping with these feelings, are described.



It is natural to feel worried when you are not sure what might happen in the future.

## Living with the fear that melanoma may come back or spread

“ I feel like melanoma is a sword hanging over my head. I guess because you are always keeping an eye on things, it’s always there – it’s like an undercurrent in your life. ”

**After a diagnosis of melanoma, life may seem less certain and out of your control.**

You may feel afraid of:

What lies ahead in terms of treatment

The impact this experience may have on your life

The affect this may have on your family

The possibility that the melanoma may come back

The possibility that the melanoma may spread to other parts of your body

The possibility that you could die

Many people worry about the possibility of getting melanoma again. Some people have this fear for years after their treatment has finished. Others feel more stressed or anxious around the time of medical check-ups or skin examinations.

“ I think it’s always at the back of your mind and you think, ‘I might get it again’. ”

These fears are common and anyone who has had melanoma might experience them from time to time. For some people, these fears can have a big impact on their mood, relationships and plans for the future. Sometimes these fears can change the way people see themselves and what they see as being important in their lives.

Some people keep these fears about melanoma to themselves and find it difficult to talk about them because others don’t seem to understand.

“ I’ve had many people say, ‘Oh you’ve just had a mole removed,’ and I’m like, ‘It’s actually cancer, believe it or not.’ ”

Friends and family may sense your fears and try to reassure you that “it’s all over” and that you “don’t need to worry anymore” about melanoma. These statements may make you feel like others don’t understand the fears you are experiencing or what it is like for you to have had melanoma.

“ Frequently, melanoma patients report that they feel like their melanoma is a 'ticking time bomb'. I often tell my early-stage patients that their melanoma is more like a 'warning shot'. It is a reminder to take sun protection seriously and to look after your skin. ”

- Dermatologist specialising in melanoma

Sometimes when fears about melanoma are very strong, a person might check their skin too often or visit doctors to try to get reassurance.

Checking your skin too often can make it harder to notice changes in spots or moles over time, as melanoma often develops slowly. You should check your skin every 3 months. This will allow you to get to know your skin and notice any changes.



Some people may avoid checking their skin or try to avoid visiting the doctor because they are afraid of getting bad news. Talking about your fears may help you find ways of dealing with them so that you don’t need to avoid important aspects of your health care.

If you find that you worry about your melanoma, it may be helpful to ask your healthcare team (GP, nurse, dermatologist) for more information. Information may make you feel like you are more in control. Your medical team has access to sophisticated tools to predict your personalised risk of getting another melanoma or your melanoma spreading elsewhere. We have developed the question list of pages 27-30 to help you think of the questions you may ask your healthcare team. If you find that you still worry about melanoma after you have information from your doctor, talking to a psychologist may help understand and cope with these emotions.

Avoiding worries can make us feel better in the short term, but it does not make the worries go away and is not effective in the long term.

# Recognising your signs of stress

**Stress is a normal reaction to learning that you have melanoma. It is common to notice changes in your body, mood and behaviour when you feel stressed.**

Common responses to stress include:

- Feeling restless or 'on edge'
- Having difficulty concentrating or making decisions
- Feeling numb or like your mind is blank
- Finding it difficult to switch off your mind or to think about things other than melanoma
- Feeling irritable or nervous
- Having difficulties falling asleep or waking up throughout the night
- Having bad dreams
- Being easily tired, worn out or fatigued
- Feeling tension in your body
- Not feeling interested in activities you usually enjoy
- Changes in the amount of time you wish to spend with family or friends
- Changes in the way you feel about sex and intimacy
- Changes in your appetite (eating more or less than usual)
- Nausea or stomach pains
- Changes in bowel movements
- Headaches

Feeling stressed can make it more difficult to cope and can sometimes lead to anxiety or depression, so it is important to try to be aware of your signs of stress.

Take a moment to notice how many of the responses above you have experienced over the past week. There are simple things you can do to try to reduce stress and the Stress Busters list below gives some examples.

## Stress Busters

- Talk to someone you trust about the way you are feeling.
- Do something relaxing like listening to music, watching a movie, or reading.
- Meditate, do yoga, or practice deep breathing.
- Ask others for help when you need it.
- Exercise regularly, if you can.
- Try to eat healthy foods.
- Don't be afraid to say 'NO!' to extra tasks.
- Try to rest and get enough sleep.
- Try to plan your days and have routines to help you feel more in control.
- Try to identify the things that are most important or necessary, and start on those first.
- Make time for yourself and the things you enjoy

# What is the difference between stress and anxiety?

While everyone feels stressed from time to time, some people experience these feelings so often or so strongly that it can affect their everyday lives. Stress is a response to feeling overwhelmed, but anxiety is feeling fear, worry or nervousness that doesn't go away.

## What are the signs of anxiety?

Signs of stress and anxiety do overlap. The list at the top of page 36 includes some common signs of anxiety. If you are experiencing some of these responses on most days, and you are feeling very worried and finding it hard to stop worrying, you may be experiencing anxiety.

Because these feelings can develop slowly over time, it can be hard to know when help is needed.

Other signs of anxiety can include:

- Avoiding certain issues or situations that are important in your life
- Feeling scared or frightened for no obvious reason
- Feeling a constant need for reassurance

There are also other physical signs of anxiety such as:

- Sweating
- Trembling
- Tingling or pins and needles
- Dizziness or light-headedness
- Feeling flushed or jittery
- Feeling a tightness in your chest
- Feeling like it's hard to breathe

These physical sensations can make you feel even more anxious because they are unpleasant.

If you think you are experiencing heightened anxiety, you can get help by talking to your GP or by calling the Beyond Blue helpline on: **1300 224 636** (24 hours, 7 days a week) or the Cancer Council helpline on: **13 11 20** (9am-5pm Monday - Friday)

## Why might I be feeling angry?

Anger is another common response to learning that you have melanoma.

### You may feel angry when thinking about:

Why this has happened to you	Delays that may have occurred with your skin examinations or your diagnosis	The effects, costs and inconvenience of treatment
The way melanoma has disrupted your life and plans	The way your family and friends are reacting	The way other people may not understand the seriousness of melanoma

### Positive aspects of anger

While anger can feel uncomfortable, it can also help you to change things for the better. For example, anger can provide energy, strength and determination during times of hardship.

### Difficulties associated with anger

Anger can be difficult to express. At times it can be hard to know what we are really angry about or why we feel so angry. Sometimes, anger can hide other painful feelings like sadness, fear or helplessness. Some people can act on their anger before they are fully aware of their feelings and can regret this later. Anger can also make you feel physically tense or agitated.

#### **Finding positive ways to express your anger can feel good and can help others to understand what you are going through.**

Here are just a few ideas:

- Try talking with someone who can help you to identify why you are feeling angry. Talking things through can help you find solutions to problems or to see things from a different perspective.
- In the heat of the moment, sometimes it can be helpful to do something physical, like going for a walk. While physical activities or sports won't change why you're feeling angry, they can be helpful as an outlet for your anger and can help you to feel less tense or agitated.
- Find ways of standing up for yourself that make you feel heard and do not upset other people.

## How can I tell if I'm depressed?

**While we all feel sad, moody or low from time to time, some people experience these feelings more intensely and for long periods of time.**

### What is depression?

After a diagnosis of melanoma, your outlook on life can change. Some people experience low mood to such an extent that it makes it difficult for them to keep up with daily activities, and they can lose interest or pleasure in the things they once enjoyed. If this is happening to you, you may be experiencing depression.

“Melanoma to me? I guess I know enough about it to be able to feel depressed.”

### How common is depression?

Depression is common. One in six Australians experience depression at some stage in their lives. The rates of depression are higher amongst people who have had cancer, with about one in three people with cancer experiencing depression at some time in their lives.

### What are some of the signs of depression?

- Feeling sad, empty, hopeless or tearful most of the day, nearly every day
- Losing interest and pleasure in activities you usually enjoy
- Avoiding friends and family
- Noticing changes in your appetite or weight
- Having difficulties sleeping
- Feeling so tired or sad that you do not want to get out of bed
- Feeling irritable or restless
- Feeling fatigued or low in energy
- Having trouble concentrating
- Feeling worthless or guilty
- Being critical of yourself
- Feeling like life isn't worth living
- Having thoughts of harming yourself or ending your life

If you or someone you know has been experiencing some of these difficulties most of the time for more than two weeks, it is important to seek professional help.

You can get help by talking to your GP or by calling the Cancer Council helpline on: **13 11 20** (9am-5pm Monday - Friday) or the Beyond Blue helpline on: **1300 224 636** (24 hours, 7 days a week).

## Thoughts and feelings about melanoma: How are these connected?

How you **think** and **feel** about melanoma can influence the way you **cope**.

When faced with melanoma, you may feel afraid and your thoughts may focus mainly on worries such as:

“ Melanoma is life threatening.  
It's only a matter of time before  
the melanoma comes back. ”

These thoughts are often automatic and can pop into our minds without us noticing or questioning them. How we feel about ourselves and our experiences can influence our thoughts and the way we react to events. It also influences what we do in order to cope with unhelpful thoughts and feelings.

Becoming more aware of our thoughts and feelings is a first step to coping well and making positive changes in our lives.

If you are noticing that you often worry about melanoma coming back, it may be helpful to talk to your doctor about your personal risk of this occurring. They have access to sophisticated tools that are helpful in predicting an individual person's risk of getting another melanoma or melanoma spreading to other parts of the body.

Knowing the facts makes it easier to cope with worries.

If you notice that you are having difficulty coping with certain situations, it can be helpful to talk with a psychologist. A psychologist can help you to better understand the connections between your thoughts and feelings, and can support you in coping as best you can with melanoma.

## How can my diagnosis affect my family and friends?

Melanoma doesn't only affect you. It also affects the people around you – your family, friends and work mates.

“ I think this has affected my mother a  
lot. I mean, it's affected all of us. ”

Your family may find it difficult to cope with your diagnosis and just like you, they may need information, help and support. Your spouse or partner may feel worried but may find it difficult to talk to you about how they are feeling, for fear of causing you even more stress. Your children can also feel worried if they are not able to talk with you about what is happening.

“ I'm sure a lot went through my husband's mind when  
I was told the first time, but he sort of didn't let on. He  
must have felt pretty tense about it all.  
I'm concerned about the way my husband will react  
because I think it's harder for them than it is for you. ”

Others may not understand the difficulties you are facing and this can make it harder for you to ask for help.

“ There are just so many people who don't understand  
how dangerous melanoma is. So yeah, there's a wrong  
perception from most people. The actual depth of what  
it means to have melanoma is missed, I think. ”

Sharing this booklet with family and friends may be one way to help those around you to understand what you're going through. It may also help your family and friends to feel more informed about your care and the things they can do to support you. Some ways family and friends might be able to help are listed on page 48.

Your family and friends can access information and support by contacting the Cancer Council Helpline on: **13 11 20** (9am-5pm, Monday to Friday) or Beyond Blue on: **1300 224 636** (24 hours, 7 days a week). They can also talk to their GP about any questions they may have.

## 5

# Coping: finding what works for you

There are many simple and useful things you can do to help you cope with melanoma. A range of support services and health professionals are also available to help you through the challenging times. You do not have to go through this alone.

## Taking care of yourself

When we look after ourselves, we are much better able to cope and enjoy our lives. Some simple and useful things you can do are:

### **Making time for yourself**

We all know it's easier said than done, but making time for yourself is important. Rather than being 'selfish', it's usually the opposite – if you make time to do the things you love, you tend to be more available to others in your life. If making time for yourself is not something you do often, or if it's easily replaced by more urgent things, consider keeping a diary and marking in time just for you.

### **Planning enjoyable activities**

Making plans to do things you enjoy or value can give you something to look forward to. It may be helpful to have a list of things you enjoy doing - so that when you have time you can choose to do something you like (for a list of enjoyable activities, see page 44).

### **Exercising and eating well**

Exercising and eating well are good for your body and your mind. Regular exercise has been shown to help people feel good and can also help with managing stress and tiredness.

### **Sleeping well**

Having a good sleep routine is important for both your physical and your mental well-being. Try to do calming things before bedtime, like reading a book, listening to music, having a hot (non-caffeinated) drink, or using lavender oil. Try to go to bed and get up at about the same time each day. Keeping electronics such as televisions, computers, tablets and mobile phones out of your bedroom can also help.

### **Looking good, feeling better**

Taking care of your appearance can help you feel good about yourself. This doesn't need to be anything fancy. It can be little things like wearing clothes that you really like and feel good in.

### **Doing as many of your usual activities as you can**

People can be comforted by keeping up their routines and their everyday contact with others. Doing the little things you usually do can help to keep a sense of normal life during stressful times.

### **Feeling prepared and in control when outdoors**

People who have had melanoma often find it useful to have a small bag packed with essential items for sun protection. By doing this, you can feel sure you will not get caught out in the sun without the things you need. Some people leave this bag in the boot of their car, ready for times when they are out and about. Useful things to pack include: a sunscreen with SPF50+, a wide-brimmed hat, sunglasses, and a long-sleeved shirt.

### **Turning to spirituality, faith or prayer**

Whether you believe in God, universal energy or the goodness in those you love, many people find that spiritual beliefs can help when we are faced with difficult times.



## Doing the things you enjoy most

Sometimes, when difficult or stressful events dominate your life, you can feel so overwhelmed that you forget to include enjoyable activities in your day. Have a look at the list below and think about the things you enjoy doing. You may also like to add to this list.

- Going for a walk in a beautiful place
- Reading a book or magazine
- Seeing a movie
- Playing with a pet
- Having a massage
- Dancing
- Doing sport or exercise
- Going out for coffee or a delicious meal
- Going on a picnic with friends or family
- Working on a hobby or trying something new that you have been wanting to do for a while
- Going for a drive somewhere you have been wanting to see
- Playing or learning to play a musical instrument
- Gardening or caring for your houseplants
- Listening to music
- Going to a concert, play, art exhibition or some other special event
- Watching your favourite sports team
- Visiting or phoning a friend
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



Developing routines can be helpful when trying to make time for yourself. Routines can help you structure your life and feel more in control, especially during difficult times.

“ I lead a very outdoor life. We kayak, we backpack, we walk, we cross-country ski - everything outdoors and I don't intend to shut myself away. So we take the best precautions that we think will work. ”



## Learning from other people's experiences with melanoma

Many people have described the importance of keeping in touch with the positive aspects of life with melanoma.

It can be helpful to keep in mind that:

- People with melanoma can lead active lives
- Treatments for melanoma are available and successful
- Your chances of surviving melanoma are better now than ever before

**Having a sense of hope can help you to cope with the challenges that melanoma can bring. It is normal not to feel hopeful right away or all of the time. Hope is a feeling that develops and changes over time.**

Here are some ideas to help you develop a sense of hope:

- Take the time to write down the things you feel hopeful about
- Talk with others about your reasons to be hopeful
- Plan your days as you have always done
- Try not to limit the things you like to do
- Look out for reasons to be hopeful in your everyday life
- Plan things to do in the future, like a holiday or weekend getaway

Some people find hope in nature or in their religious or spiritual beliefs. Others find hope in hearing stories about people who have had melanoma and who are leading happy, active lives.

Sometimes the most difficult experiences are the ones which also help us to grow. Having melanoma can be difficult. Some people find it can also be an opportunity to reflect on what is important in their lives.

## Taking an active approach to dealing with melanoma

Research suggests that being active in dealing with melanoma can help you to cope well. Having an active approach to living with melanoma includes:

Using sun protection when outdoors and in the sun

Getting the information you need about melanoma

Going to your appointments

Checking your skin as recommended on pages 19-20

Generally taking care of yourself

Seeking help and support when needed

For some people, learning more about melanoma can help them to feel capable and in control. Other people feel overwhelmed by lots of information or simply don't feel they need to know about the details. You can choose how much or how little information you need at any given time, and your preferences for information may change over time.

“*First time I was diagnosed with melanoma, it did frighten me. The second time I had more knowledge and I got more information. I think that in itself made me a little bit happier, even though it was still frightening.*”

Often a good place to start is to talk with a member of your health care team such as your GP, dermatologist, melanoma nurse or psychologist. We have developed the Question List on pages 27-30 to help you think about the types of questions you might want to ask.



## How can I meet other people who have had melanoma?

Support groups are formed and run by people who share a common life experience. These groups are a place where you can find and offer support to other people in a similar situation and learn from one another's experiences.

Most people enjoy the mutual support that group members are able to give one another. This support can be very powerful. The sharing of information can also be helpful. Being able to share your thoughts, feelings and concerns with others who understand and have been through similar experiences can be very helpful in coping with melanoma.

“*Now I make sure I feel supported. I mean, you feel as though you're part of a family of melanoma survivors, a member of a club. That's important.*”

If you are interested in joining a support group, call the Cancer Council on: **13 11 20** (9am-5pm Monday to Friday) or Melanoma Patients Australia on **1300 88 44 50** (9am-5pm Monday to Friday). They can help you to find a group in your area.

## How can my family and friends help?

“ I don't want to burden others with my worries, I'm fine! ”

Often people are concerned they will be a burden on others if they talk about their worries. They can feel concerned about 'bringing others down'. While it can take courage to share your thoughts and feelings with others, doing so can bring people closer together and can help those around you to understand why you might seem a little different from your 'usual self'.

### Helping others to help you

Sometimes people try to help in ways that may not feel helpful to you. It's okay to let people know if they are not being helpful and to suggest other ways in which they could support you. Often it's help with the practical things, like going to appointments with you or doing jobs around the house, that can really make a difference. Often people like and want to help, but they may not know what you really need.

#### **If you are a friend or family member of someone with melanoma these are just some of the ways you might be able to help:**

- Asking how your friend is going and being ready to listen
- Listening to their concerns so you can try to understand what they're going through
- Being silent to give time to think
- Respecting their privacy if they do not want to talk about it
- Chatting about things other than melanoma
- Avoiding giving advice, empty reassurances or pushing your beliefs
- Avoiding going into long stories about other people with cancer
- Continuing to invite and include them in social events but also respecting their decision not to attend
- Asking your friend about what you can do to help



## How can a psychologist help?

**At times you may feel the need to 'look on the bright side' or 'stay strong' when really, you feel very different on the inside. You may also feel grateful for the medical care you've received and the thought of voicing concerns or asking for help can make you feel uncomfortable.**

“ I guess it's a bit of that macho thing of, 'Well I'm alright'. ”

It can be difficult to acknowledge how you are feeling, especially if you think you 'should' be feeling a certain way. While pushing away difficult thoughts or feelings can seem like a good strategy in the short term, research shows that avoiding worries or distressing thoughts can increase feelings of sadness and anxiety in the long term.

You may feel that talking with someone other than your family and friends would be helpful. Joining a support group is one option, but if you are finding things really hard, you might try talking to your GP to ask if he or she can recommend a psychologist for you. A list of psychologists can be found on the Australian Psychological Society website ([www.psychology.org.au](http://www.psychology.org.au)) or by contacting the Cancer Council ([www.cancer.org.au](http://www.cancer.org.au); 13 11 20)

Psychologists have specialised training in listening to and understanding people's thoughts, feelings and behaviours. They can work with people to explore new ways of thinking and behaving that can make it easier to cope during difficult times, or when thoughts, feelings and worries become overwhelming.

## What can influence how a person copes?

How you cope after a diagnosis of melanoma can be influenced by a range of factors.

Younger people may feel angry, confused or frightened about the impact of melanoma on their future.

People who are experiencing marital or family difficulties may feel like they don't have enough support.

Parents and grandparents often feel guilty about the impact of melanoma on their children and may worry about their children's risk of developing melanoma in the future.

Men often delay or put off seeking medical attention when it's needed.

People who have had to face stressful life events in the past may experience greater stress during melanoma diagnosis and treatment.

People with financial concerns may be worried about the additional costs of treatment and taking time off work.

People who have experienced anxiety or depression in the past may be at increased risk of experiencing these difficulties again.

People with melanoma on parts of the body that are usually seen by others (such as their face or hands) may be concerned about scarring and the way treatment may change their appearance.

People who have had problems with alcohol or drugs may experience more emotional distress.

A range of health professionals and support services are available to help you through the challenging times. You do not have to go through this alone. For a list of support services, please turn to pages 61 and 62.

## 6

# How can I keep track of my care?

Keeping track of your care after a diagnosis of melanoma is important. This section includes space for you to record important information that may be valuable in the future.

Try to keep this section of the booklet up-to-date.



## Previous non-melanoma skin cancers

Date	Hospital or clinic	Doctor	Type of skin cancer	Location on my body	Treatment

## Other tests I've had

It is also important to keep a record of the different tests (such as biopsies, blood tests, imaging) you have and their outcome.

Date	Hospital or clinic	Doctor	Type of test	Location on my body	Test result	Treatment







## 7

# Where can I get more information?

## Helpful websites

While not all websites are accurate, the Internet can be a useful source of information. Here is a list of websites we recommend you visit if you would like more information about melanoma or available support services. Remember, it is always important to discuss the information you find on the Internet with your health care team.

### Australian websites

Australasian College of Dermatologists	<a href="http://www.dermcoll.edu.au">www.dermcoll.edu.au</a>
Australian Cancer Trials	<a href="http://www.australiancancertrials.gov.au">www.australiancancertrials.gov.au</a> <a href="http://www.cancer.net">www.cancer.net</a>
Australian Melanoma Research Foundation	<a href="http://www.melanomaresearch.com.au">www.melanomaresearch.com.au</a>
Australian Psychological Society	<a href="http://www.psychology.org.au">www.psychology.org.au</a>
Beyond Blue	<a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a>
Cancer Council Australia	<a href="http://www.cancer.org.au">www.cancer.org.au</a>
Cancer Institute NSW	<a href="http://www.cancer.nsw.gov.au">www.cancer.nsw.gov.au</a>
Centre for Genetics Education	<a href="http://www.genetics.edu.au">www.genetics.edu.au</a>
Melanoma Institute Australia	<a href="http://www.melanoma.org.au">www.melanoma.org.au</a>
Melanoma Patients Australia	<a href="http://www.melanomapatients.org.au">www.melanomapatients.org.au</a>
Mensline	<a href="http://www.mensline.org.au">www.mensline.org.au</a>
Psychology Board of Australia	<a href="http://www.psychologyboard.gov.au">www.psychologyboard.gov.au</a>
SunSmart Campaign	<a href="http://www.sunsmart.com.au">www.sunsmart.com.au</a>

### International websites

American Academy of Dermatology	<a href="http://www.aad.org">www.aad.org</a>
American Cancer Society	<a href="http://www.cancer.org">www.cancer.org</a>
British Association of Dermatologists	<a href="http://www.bad.org.uk">www.bad.org.uk</a>
GenoMEL, The Melanoma Genetics Consortium	<a href="http://www.genomel.org">www.genomel.org</a>
Macmillan Cancer Support	<a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a>
Melanoma Hope Network	<a href="http://www.melanomahopenetwork.org">www.melanomahopenetwork.org</a>
Melanoma Research Foundation	<a href="http://www.melanoma.org">www.melanoma.org</a>
National Cancer Institute (USA)	<a href="http://www.cancer.gov">www.cancer.gov</a>
New Zealand College of Dermatologists	<a href="http://www.dermnetnz.org">www.dermnetnz.org</a>

## Useful telephone numbers

Australian Psychological Society	1800 333 497
Beyond Blue	1300 224 636
Cancer Council Helpline	13 11 20
Centre for Genetics Education	(02) 9462 9599
Lifeline	13 11 14
Melanoma Institute Australia	(02) 9911 7200
Melanoma Patients Australia Peer Support Helpline	1300 88 44 50
Mensline: Information and support for men	1300 789 978
NSW 24-Hour Mental Health Helpline	1800 011 511
Psychology Board of Australia	1300 419 495

## Glossary: Some words you may need to know

**Actinic keratosis (sun spot):** These are rough, red and scaly spots found on sun damaged areas of the skin and, in rare cases, may be the beginning of a squamous cell carcinoma.

**Advanced melanoma:** melanoma that is no longer localised and has spread. See stage III and IV (metastatic melanoma).

**Basal Cell Carcinoma (BCC):** This is the most common type of skin cancer. BCCs grow slowly in areas of the skin that have been exposed to the sun and almost never spread to other parts of the body. Treatment is by surgical removal or sometimes by medication applied to the skin.

**Benign:** Not cancerous or malignant.

**Breslow thickness:** A measure of the thickness of a melanoma in millimetres. Melanomas are classified as in situ (on the skin surface only), thin (1 mm or less), lower intermediate (between 1.1 mm and 2 mm), higher intermediate (between 2.1 mm and 4 mm), or thick (more than 4 mm). The depth of the melanoma is important because the deeper the cancer cells have grown into the skin, the more likely it is that the cancer will come back or spread to the lymph nodes or elsewhere in the body.

**Cancer:** The uncontrolled growth of abnormal cells in the body. Cancerous cells are also called malignant cells.

**Cancer recurrence:** See recurrent melanoma.

**Carcinoma:** Cancer that begins in the skin or tissue that lines the inner or outer surfaces of the body.

**CDKN2A:** CDKN2A is short for Cyclin-Dependent Kinase iNhibitor 2A. It is a gene that we all have. CDKN2A produces a protein (called p16) that plays an important role in controlling the growth of cells. Mutations in the CDKN2A gene are associated with an increased risk of developing some cancers, including melanoma.

**Cell:** The basic building block of the body. People are made of billions of cells that are adapted for different functions.

**Chemotherapy:** The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth. For more information, talk to your doctor or visit the Cancer Council website ([www.cancer.org.au](http://www.cancer.org.au)) to access a free booklet called Understanding Chemotherapy.

**Clark level:** A number from 1 to 5 that describes how far a melanoma has penetrated into the skin, with 5 being the deepest.

**Clinical trial:** Research testing the safety and effectiveness of new treatments.

**Dermatologist:** A doctor who specialises in the diagnosis, treatment and prevention of skin diseases and skin cancers, including melanoma.

**Dermis:** One of the two main layers of the skin. The dermis is the second layer of the skin. It contains the roots of hairs, glands that make sweat, blood and lymph vessels, and nerves.

**Dysplastic naevus:** A mole that looks different to normal moles because it is uneven in colour, has an irregular border, or is larger than normal moles.

**Early stage melanoma:** see stage 0, I and II melanoma.

**Epidermis:** The top or outer layer of the skin. It does not contain blood or lymph vessels.

**Family cancer clinic:** Family cancer clinics provide counselling and information for families with a history of cancer. Geneticists and genetic counsellors can provide information on genetic factors associated with cancer, individual risk of developing cancer, guidance regarding screening and cancer risk reduction strategies, and emotional support. They also provide genetic testing for cancer risk where appropriate. For more information, visit: <http://www.genetics.edu.au/Genetics-Services/family-cancer-services>.

**Gene:** A unit of hereditary information (or segment of DNA) which is passed from parent to child.

**Gene mutation:** A permanent change in the structure of a gene (DNA) that may (or may not) be associated with an increased risk of developing some diseases, including melanoma.

**General practitioner (GP):** A doctor who specialises in the comprehensive and coordinated provision of health care to individuals and families, including referral to other specialists as needed.

**Genetic counselling:** Genetic counselling provides an individual or family with information and support regarding health concerns that run in their family. Genetic counselling may involve the diagnosis of a genetic condition, and the provision of information and supportive counselling by a team of health professionals so that families and individuals may be better able to adjust to diagnosis. Follow-up counselling can be offered to ensure ongoing support and information.

**General surgeon:** A doctor who specialises in general surgery who may also remove skin cancers, including melanoma.

**Genetic susceptibility:** An inherited increase in a person's risk of developing a disease.

**Genetic testing:** Genetic testing is a type of medical test that identifies changes in chromosomes, genes or proteins. Most of the time genetic testing is used to find changes (or mutations) that are associated with inherited conditions.

**Haematogenous:** The spread of melanoma through the blood stream.

**Immunotherapy:** Drugs that work by activating the body's own immune system to fight melanoma cells.

**Invasive melanoma:** A melanoma that has grown past the epidermis (the outer layer of skin) and has invaded the dermis (the inner layer of skin) or below.

**Localised melanoma:** A melanoma that has not spread beyond its starting point on the skin.

**Lymph node:** A small, bean shaped structure that forms part of the lymphatic system and is also known as a lymph gland. We have lymph nodes in the neck, armpit, groin and abdomen.

**Lymph vessel:** A thin tube that carries tissue fluid (lymph) all over the body.

**Lymphogenous:** The spread of melanoma through the lymphatic system.

**Lymphatic system:** A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat. The lymphatic system is part of the body's immune system and helps the body fight infection.

**Lymphoscintigraphy:** A procedure in which a radioactive substance is injected into the skin to identify the sentinel lymph node.

**Malignant:** Cancerous.

**Medical oncologist:** A doctor who specialises in the medical treatment of cancer.

**Melanin:** The brown pigment that gives the skin its colour and helps to protect the body against the damaging effects of ultraviolet radiation from sunlight and solariums.

**Melanocyte:** A cell in the top layer of the skin (epidermis). Melanocytes produce melanin.

**Melanoma:** Cancer of the melanocytes. Melanoma usually appears on the skin but may affect the nervous system, eye or mucous membranes (e.g. the lining of the mouth and nasal passages).

**Melanoma in situ:** A melanoma remaining in the top layer (epidermis) of the skin. The melanoma has not begun to invade the second layer (dermis).

**Melanoma nurse:** A nurse who has extra training in assisting you through all stages of your melanoma diagnosis and treatment.

**Melanoma risk:** The likelihood that a person may develop melanoma in the future based on scientific evidence and medical knowledge.

**Metastatic melanoma:** Melanoma that has spread from where it began (primary melanoma) to another part of the body (secondary cancer). Also called stage III or IV melanoma.

**Mitotic rate:** Indicates the rate at which melanoma cells are dividing. A higher mitotic rate means that more cells are dividing and that the melanoma is more likely to grow and spread.

**Mole:** A small, often dark spot in the skin which arises from skin cells called melanocytes. Also called a naevus.

**Pathologist:** A doctor who specialises in the examination of skin and body tissue

in a laboratory to diagnose diseases, including melanoma.

**Plastic surgeon:** A doctor who specialises in skin surgery and performs operations to remove skin cancers, including melanoma.

**Primary melanoma:** The original melanoma. Cells from the primary melanoma may break away and be carried to other parts of the body, where secondary cancers (metastases) may form.

**Prognosis:** The expected outcome of a person's disease, including the risk of recurrence in the future.

**Psychiatrist:** A doctor who specialises in the medical treatment of mental illness.

**Psychologist:** A health professional who specialises in the diagnosis and treatment of psychological difficulties, and provides emotional care and support during times of stress.

**Radiation oncologist:** A doctor who specialises in the treatment of cancer with radiotherapy.

**Radiotherapy:** The use of radiation (usually x-rays or gamma rays) to destroy cancer cells. For more information, talk to your doctor or visit the Cancer Council website ([www.cancer.org.au](http://www.cancer.org.au)) to access a free booklet called Understanding Radiation Therapy.

**Recurrent melanoma:** The return of melanoma after treatment and after a period of time during which the melanoma was not detected. The same melanoma may come back where it first started or somewhere else in the body. The development of another skin melanoma is usually not a recurrence, but rather a new primary melanoma.

**Risk factor:** Something that increases a person's likelihood of developing a disease such as melanoma.



