

Understanding Early Melanoma



*A guide to
early melanoma*

Melanoma
New Zealand





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ABOUT THIS BOOKLET

More than anything else, we want you to know that you are not alone; that there is help and support for you both through Melanoma New Zealand, your medical team and district health board and other organisations whose role is to help you and your family through your cancer diagnosis and treatment, and life beyond.

Receiving a diagnosis of melanoma can be frightening. You'll probably have many questions about melanoma and what will happen next. This booklet is designed to answer some of the questions you may have about the diagnosis and treatment of your early melanoma and how to look after yourself afterwards.

Just remember that treatment options are evolving all the time, and outcomes for melanoma patients are improving.

We can't tell you what the best treatment will be for you; this is something you have to work out with the team of health professionals caring for you. However, we can help you understand some of what you will experience from the time you are diagnosed, some of the terminology that you will hear, some of the tests and treatment options that may be offered to you, and some of the issues you may face through this period of your life.

At the end of the booklet we give you some useful resources and links where you can get more information, support or help.

We also encourage you to share this booklet with your whānau/family and friends to help them understand what melanoma means for you, and so they have a better idea of how they might be able to support you.

Melanoma NZ

Melanoma New Zealand is a registered charitable trust devoted to issues relating to melanoma and:

- provides information about all aspects of melanoma;
- promotes regular skin checks for early detection;
- advocates to increase access to high quality clinical care.

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EARLY MELANOMA

About Melanoma

Melanoma is a type of skin cancer that develops from pigment producing cells in the skin, called melanocytes, which are the cells responsible for the colour of our skin, eyes and hair. When these cells divide uncontrollably it results in melanoma. Melanoma can be more serious than other types of skin cancer, such as basal cell carcinoma or squamous cell carcinoma; it can progress quickly and can be life-threatening.

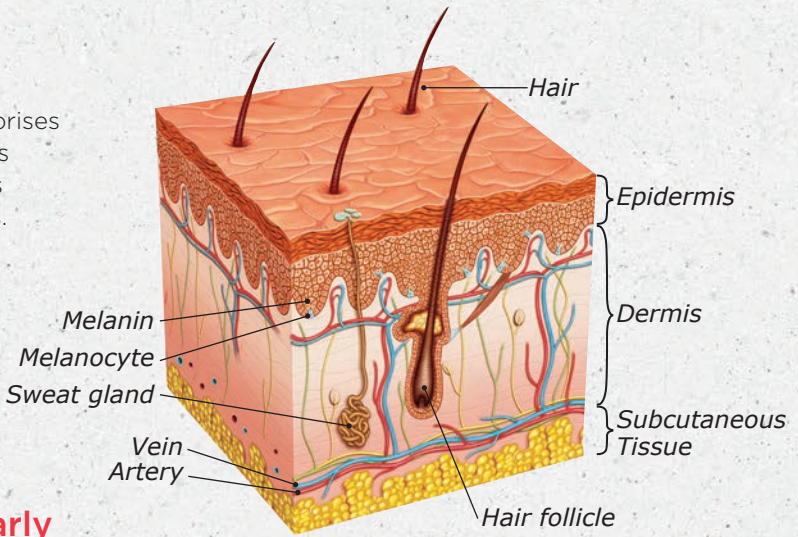
Cancer occurs when some cells in the body don't obey the "instructions" about how to divide, how to grow and when to die. This happens when the genetic information in the cells is damaged, for example by exposure to the sun and damaging ultraviolet (UV) rays. When this happens, cells don't die (to be replaced with new cells) when they are supposed to, and they grow and divide more rapidly than they are supposed to. In addition, the body's immune system, which normally eliminates such "rogue" cells, fails to destroy these cells. When these things happen together the cells may grow into a mass or a lump that becomes a cancerous tumour. If left alone, a malignant or cancerous tumour can spread into surrounding tissues, your lymphatic system and to other parts of the body.

Melanoma in New Zealand

- Over 4000 people are diagnosed with either melanoma *in situ* or invasive melanoma every year in New Zealand – that's about 13 people every day.
- It accounts for nearly 80% of all skin cancer deaths.
- Over 300 New Zealanders die of melanoma every year.
- New Zealand has one of the highest melanoma incidence rates in the world.
- 70% of melanoma cases occur in people aged 50 years and older.
- Melanoma rarely occurs in children.
- Although Māori and Pacific people have a lower chance of getting melanoma, they often have thicker, more serious melanomas.
- Death rates are higher among men.

Your Skin

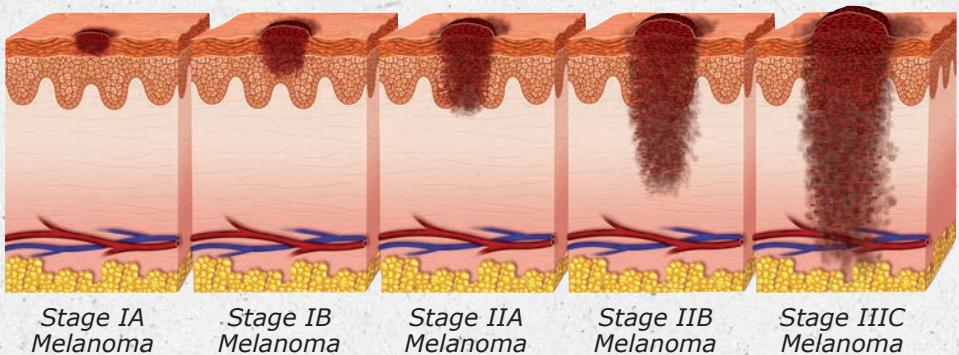
Your skin comprises two main layers - the epidermis and the dermis.



What is Early Melanoma?

Early melanoma is melanoma that has not spread to other parts of your body.

Melanoma usually starts in either a mole or normal looking skin. It develops from melanocytes that grow and divide faster than they should, and grow into the underlying layers of your skin. On the surface of your skin a melanoma may look like a dark spot or an unusual mole. It may change quite rapidly, changing shape and size. As the melanoma grows it can progress into the lower layers of your skin. It can spread into your lymphatic system as well as other parts of your body.



Early melanoma is unlikely to spread into the blood or lymphatic vessels and is usually cured with surgery. Early treatment reduces the likelihood that your melanoma will spread.

Symptoms

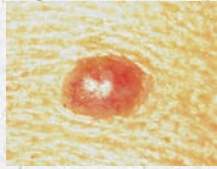
Melanoma often starts with changes in a mole or freckle you already have, but about half of all melanomas start with a change in what was normal looking skin. The first symptoms of early melanoma are changes in the skin and it is important that if you notice changes you talk to your doctor.

The ABCDE of Melanoma

The things to look for are asymmetry, an irregular border, colour, difference compared with normal moles, and change or evolution.

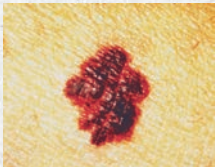


Asymmetrical

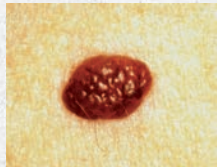


Symmetrical

Asymmetry: melanomas are more likely to be asymmetrical or have an irregular shape, compared with a normal mole or freckle with a symmetrical shape.



Irregular Border

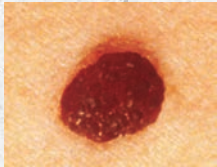


Clear Border

Border: they are also more likely to have an irregular or jagged or poorly defined border; normal moles have smoother, clear borders.



Colour Difference

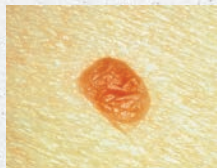


No Colour Difference

Colour: melanomas tend to be multi-coloured with different colours or shades rather than being all one colour. They may be brown with black, red, pink, white or blue tints, while normal moles and freckles are usually just brown.



Different



Normal

Different: looks different from other lesions, sometimes called the 'ugly duckling'*.

Evolving: Harmless moles usually stay the same size, shape and colour for many years, but melanomas change size, shape and colour.

* In some countries the 'D' refers to diameter, and melanomas are generally bigger than 6mm.

Other Symptoms

Other symptoms include:

- the spread of pigment or colour from the border of a spot into surrounding skin;
- a change in the surface of a mole – scalliness, oozing, bleeding, or the appearance of a lump or bump.

Types of Melanoma

Like some other cancers, not all melanomas are the same; there are different types:

Superficial spreading melanoma is the most common and is typically found on the arms, legs, back and chest. They grow slowly at first and spread out across the surface of the skin.



Nodular melanoma is the second most common type of melanoma and it can grow more quickly than the other types. It more commonly occurs on the chest, back, head and neck, and can lose colour as it grows, becoming red rather than black.



Lentigo maligna melanoma is less common and usually occurs in older people and in areas of skin that have had a lot of sun exposure, often the face and neck. They are very slow growing and can be less dangerous than other types of melanoma.



Acral Lentiginous melanoma occurs on the palms of the hands, soles of the feet or under finger and toe nails. It is the rarest type of melanoma and is more common in people with brown and black skin, and less common in those with fair skin, as those people are more likely to get sun-related melanoma; the causes of acral lentiginous melanoma are unknown but it is not related to sun exposure.



Staging

When you are diagnosed with melanoma your cancer will be “staged”. The stage is determined by the thickness of the cancer (also known as Breslow thickness), and whether or not it has spread to your lymph nodes and other parts of your body (metastases). How far advanced the melanoma is when it is diagnosed strongly influences your prognosis. For people who are treated early, when melanoma affects only the superficial layers of the skin, the prognosis is excellent and the disease is often curable. Once the cancer spreads to other parts of the body, melanoma can be difficult to treat.

Understanding Staging

There are different ways in which melanoma is described and the “codes” used might be confusing and hard to understand. However, you need to understand your diagnosis and how far your melanoma has spread in order to make informed decisions about your treatment and care. So it is important to have some understanding of what staging is and what it means for you.

When you have a biopsy or when your melanoma is surgically removed it will be investigated in a medical laboratory and your doctor will be sent a histology report. In that report the characteristics of your melanoma will be described; it will be staged and given a TNM classification where T is the primary tumour, N is regional lymph nodes and M is distant metastasis. Early melanoma is stage 0, I or II.

Stage 0 TIS, NO, MO	<i>In situ</i> , meaning that it involves the epidermis but has not spread to the dermis (lower layer).
Stage IA T1a or T1b, NO, MO	Melanoma is less than 0.8 mm in thickness with or without ulceration, or it is between 0.8 and 1.0 mm with or without ulceration and appears to be localised in the skin.
Stage IB T2a, NO, MO	Melanoma is between 1.0 and 2.0 mm thick without ulceration. It appears to be localised in the skin.
Stage IIA T2b or T3a, NO, MO	Melanoma is between 1.0 mm and 2.0 mm in thickness with ulceration or it is between 2.0 and 4.0 mm and is not ulcerated. It appears to be localised in the skin.
Stage IIB T3b or T4a, NO, MO	Melanoma is between 2.0 mm and 4.0 mm in thickness and is ulcerated, or it is thicker than 4.0 mm and is not ulcerated. It appears to be localised in the skin.
Stage IIC T4b, NO, MO	Melanoma is thicker than 4.0 mm and is ulcerated. It appears to be localised in the skin.

DIAGNOSING EARLY MELANOMA

If you notice changes in your skin or any of the ABCDE signs, or other symptoms, your first “port of call” is your General Practitioner (GP) or your family doctor. Your GP should examine your skin – not just the mole or lesion you are worried about. Your doctor should use a dermatoscope (a skin surface microscope) to look at your skin, and if they suspect melanoma may also feel the lymph nodes near the suspicious mole or lesion. If your doctor is concerned that you may have a melanoma, he or she may do a biopsy themselves or refer you to a specialist.

Biopsy

An excisional biopsy is a simple surgical procedure in which the lesion is removed and sent to a laboratory for analysis. Sometimes this might be done by your GP or by a specialist.

You will be given a local anaesthetic and then a scalpel is used to remove the mole and some of the surrounding tissue. You may have stitches to help the wound to heal.



The tissue that is removed is sent to a pathology laboratory for examination and it takes one to two weeks to get the results; a follow-up appointment may be arranged. You will find out if melanoma is present and what stage it is, how thick it is, and other information such as how rapidly the cells are dividing (mitotic rate), ulceration, regression and excision margins.

If the tests show you have melanoma, you may have surgery to remove a wider margin of surrounding skin – see page 15 for information on treatment.

If melanoma is confirmed and confined to the epidermis, then it is *in situ*; if it has spread to the dermis it is invasive; and if it has spread to other parts of your body it is metastatic.

Depending on the results of the biopsy additional testing may be recommended. This is more likely for thicker melanomas or if you have other risk factors.

Fine Needle Aspiration

If your doctor suspects that your melanoma has spread to your lymph nodes, you may have a fine needle aspiration (FNA) biopsy in which very small pieces of the lymph node are removed with the needle and then examined under a microscope.

Blood Tests

Blood tests may be taken to check your general health if you have symptoms besides changes in your skin or a mole, to rule out other possible causes of your symptoms, such as infection. They may include a blood count to check on blood cells, and tests to check how well your liver and kidneys are working.

Ultrasound

Ultrasound uses sound waves to create a picture of tissues inside your body and may be used to guide needles in an FNA biopsy (see above), or to measure the size of the lymph nodes nearest your melanoma.

WAITING FOR RESULTS

It can be a very difficult time waiting for test results, and it takes one to two weeks for your test results to be ready.

It is normal to feel anxious, apprehensive or frightened about what your test results will tell you, and what they may mean for your future. You may fluctuate between feeling that the news will be bad, and feelings of disbelief or denial; that you couldn't possibly have cancer. You may feel restless and worried, and have a tendency to repeatedly think about the worst case scenario.

It is really helpful if you have someone you can talk to – your partner, a family/whānau member or close friend. Melanoma New Zealand can provide support for you during this time. In addition, each district health board (DHB) has its own support services (psychology and social work) available for people being tested and treated for cancer.



WHAT YOU SHOULD ASK

Talking with your Doctors and Health Care Team

Asking questions about your diagnosis and your treatment will help you feel more in control of what happens to you, more involved in your care, and will also make the decision making process easier.

You may have a lot of questions for your doctor and clinical team, but often those questions might occur to you over a period of time. You may find it helpful to write down your questions so that you don't have to remember them at your appointments, or forget to ask an important question. It can also be very helpful to take a support person – a family/whānau member or close friend – with you to appointments. He or she may think of question you haven't thought of or remember questions you might have forgotten.

Sometimes you get a lot of information in a short space of time at appointments, so you might want to write down the answers to your questions. Likewise, having someone there to support you will help; they can write things down for you and may remember things you have been told and later forget.

You might even want to record your discussions with your doctors, with their consent, to listen to later.

It can be difficult to remember everything, take everything in or understand the significance of everything you are told.

If you don't remember the answer to a question, or don't understand what you have been told, you can ask more questions or for better or simpler explanations. This is an important part of understanding what is happening and an important part of you making informed decisions about your care and treatment.

Ask your doctors to write down anything you don't understand, or terminology you are not familiar with. You can even ask them to draw you a diagram if that will help you understand what they are telling you.

Your doctors must obtain your informed consent before treatment is started. To be able to give them informed consent you must understand what the treatment is, what it means for you, how it is expected to work, and what the risks, benefits, side-effects and alternatives are.



Important Questions to Ask

Before Diagnosis

- Why am I having these tests?
- What will the tests involve?
- When do I get the results?
- Can I bring someone with me when I get the results?

At Diagnosis

- What is my stage of melanoma and what does that mean?
- Who will be part of the multi-disciplinary or clinical team looking after me?
- Do I need any further tests or scans before my treatment?

Discussing Treatment

- When will my treatment start?
- What will happen if I delay my treatment so I can fully explore my options before making a decision?
- Are there any alternative surgeries/medical treatments[†] that could be considered besides the one you are offering or suggesting?
- What is the reason for the treatment you have suggested?
- Is the treatment you are suggesting recommended in the *Clinical Practice Guidelines for the Management of Melanoma in Australia and New Zealand*, and if not, what is your rationale for the treatment you are suggesting?
- Should I consider getting a second opinion if the surgery/treatment is complex or controversial?
- Would there be different treatment options if I were treated privately?
- What are the risks and side-effects of treatment?
- Will the treatment cause me a lot of pain, and if so how will we deal with that?
- Can I have a family/whānau member or friend with me while I'm having the treatment?
- Is there anything I can do to help me cope with the effects of treatment?[†]

[†] For questions you may want to ask about complementary and alternative therapies for treatment or alleviating the effects of treatment or for improving the quality of your life living with cancer see the section on Complementary Therapies on page 24.

- What would happen if I decided to stop my treatment at any point?
- What do you expect will happen if I choose not to have some or all of the treatment you are suggesting?
- How will I know if the treatment has worked?

After Treatment

- What is my prognosis and what are my chances of recurrence?
- What are the long-term effects of the cancer and its treatment?
- How can I reduce the risk of the cancer coming back?
- What symptoms should I watch for?
- What type of follow-up will I need after treatment?
- Who do I contact if I have a problem in between follow-up appointments?
- How will we know if the cancer has come back? What would my options be if that happens?
- What support services are available for me and my family/whānau?



TREATMENT OPTIONS

Cancer treatments are changing all the time and treatment for each different cancer, and different stages of the same cancer. Your treatment may be different from someone else's depending on what your clinical team believes will work best for you. More frequently now doctors can offer targeted treatments. Ongoing research gives us more information on which treatments work best for different types and characteristics of cancer, including melanoma. So, the treatment plan worked out for you might be different to the treatment plan for someone else with melanoma.

However, there are still broad categories of treatment types which you are likely to be offered.

PLANNING YOUR TREATMENT

You will be cared for by a team of health care professionals that may include:

- a GP who is responsible for your general health and referral for specialist treatment;
- a general surgeon;
- a plastic surgeon;
- a dermatologist (skin disease specialist);
- a melanoma clinical nurse specialist, who provides support to you and your family/whānau and can help to co-ordinate your care;
- pathologists, who advise on the type and extent of the cancer.

Depending on your treatment you might also have:

- a physiotherapist, who helps treat your body so you can cope with the physical effects caused by the cancer, surgery and treatment side effects;
- an occupational therapist, who helps you with everyday tasks like bathing, dressing and cooking;
- a pharmacist, who gives advice on medication;
- a dietitian, who gives advice on nutrition;
- psychologist and social worker who can help support you.



Your Clinical Nurse Specialist

Your melanoma clinical nurse specialist (CNS) will be an important point of contact for you. This role has evolved to improve your experience as a melanoma patient. Key aspects of the CNS role are patient support, care co-ordination and management of complex needs.

Your CNS will provide you with a single point of contact throughout your journey and has close links within your health team and can refer you to other professionals if needed. CNSs offer:

Resources:

- Patient information resources.
- Fertility advice and referral to other professionals as appropriate.
- Informal discussion and clarification for you and your family/whānau.
- Ensuring you are informed and can make decisions about your care (see Important Questions to Ask on page 11).

Complex Symptom Management

- Phone assessment of symptoms you are concerned about.
- Clinic support at appointments.

Patient Advocate and Supportive Care

- Transport issues.
- Cancer support – psychosocial referral and input for you and your family/whānau.
- Cancer Society of New Zealand liaison nurses.
- Specific input from cultural support services.



TREATMENT FOR EARLY MELANOMA

The treatment for early primary melanoma – that is stage 0, I or II melanoma – is wide local excision surgery and possibly sentinel node biopsy (SNB).

Wide Local Excision

Often the melanoma is removed in the excisional biopsy, but surgery called wide local excision is undertaken and removes normal skin around the melanoma and layers of skin deeper than the melanoma. This is to ensure that any high-risk cells related to the primary tumour are removed as well, which reduces the chance that your cancer will recur locally. How much tissue is removed can depend on the thickness of your melanoma. For example, if your melanoma is under 1 mm thick, the wide excision may be 10 mm, but if it is over 2 mm thick, the wide excision may be 20 mm.



Your wide local excision is most likely to be done under a local anaesthetic. If your wound is small it may require just stitches or staples, but if your wound is larger, you may need a flap skin graft. After your wound heals you will be left with a scar; how big this is depends on a number of factors, including the type of surgery you have had, and how well you heal.

Pathology Report

The tissue removed in a wide local excision is sent to a pathologist for examination. You and your doctor will be sent copies of the pathologist's report, which will provide important information about your melanoma.

The report will include information on the type of melanoma you have, such as thickness or depth of the melanoma, if ulceration was present, the growth phase, the presence or absence of melanoma cells in the normal tissue at the margins of your melanoma, mitotic rate or how fast the melanoma cells are dividing. The report also tells you the stage of your melanoma (see page 7 for more information on staging).

For people with early melanoma, the most important information is thickness, ulceration, mitotic rate and satellitosis. This information will help your health team advise you if further investigations or treatment is recommended. Most people with early melanoma only have surgery, with or without skin graft or skin flap surgery.

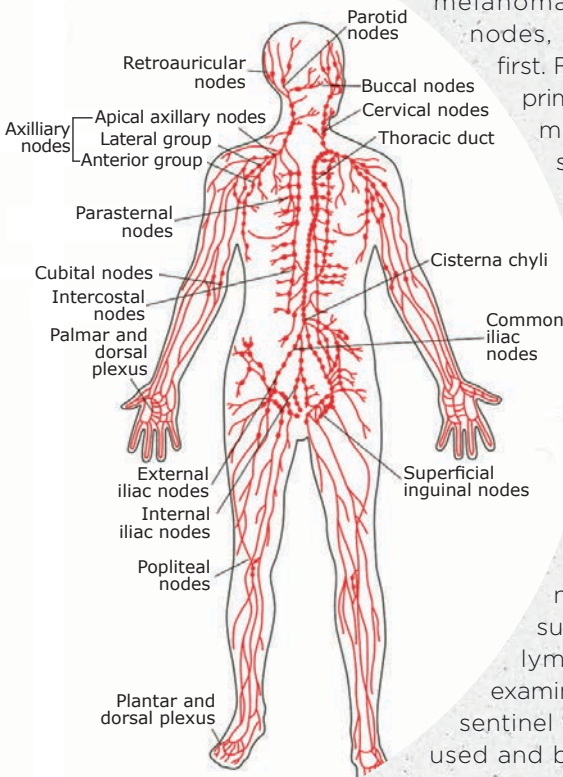
Skin Grafts and Flaps

If a lot of skin is removed during the wide local excision, you may need a skin graft or skin flap. A skin graft involves taking skin from another part of your body to replace the skin that has been removed with the melanoma in the excision.

Some melanoma patients have skin flap surgery, which is thicker than a skin graft and involves tissue being manipulated and moved into the area where the melanoma has been removed. It is more complex surgery than a skin graft, and involves cutting a flap of skin that is left partially connected so that it still has a blood supply. The flap is moved over your wide excision wound and stitched in place. Most commonly patients are discharged from hospital the same day as the procedure.

Sentinel Lymph Node Biopsy

Your lymphatic system



An important question when you have had melanoma diagnosed is has your melanoma spread beyond the surface layers of skin. The most common place for melanoma cells to spread to is the lymph nodes, so your doctor will examine them first. For people diagnosed and treated for primary melanoma – that is, stage I and II melanoma – and who have no other symptoms, further investigations are not required.

However, if lymph nodes near your melanoma are enlarged or hard, your doctor may perform a fine needle aspiration; very small pieces of the lymph node are removed with a very fine needle and then examined under a microscope. If anything suspicious is found, that node will be removed.

You may be offered a sentinel lymph node biopsy (SLNB), which involves surgically removing all of the sentinel lymph node or nodes, which are then examined under a microscope. To find the sentinel lymph node, a radioactive tracer is used and blue dye is injected into the site of the melanoma.

If there are no melanoma cells in the sentinel nodes, no more lymph node surgery is needed because it is unlikely the melanoma would have spread beyond this point. If melanoma cells are found in the sentinel node, further discussion is required with your specialist.

A negative sentinel lymph node biopsy indicates a lower risk that the cancer has spread than if the biopsy shows melanoma cells. However, a negative SLNB does not mean you don't have, or won't develop advanced melanoma, and a positive SLNB doesn't necessarily mean you will, but does identify a higher risk group.

Adjuvant Treatment

When people are told they have cancer, chemotherapy is probably the first treatment they associate with their diagnosis. Many cancer patients also have radiotherapy. However, these treatments are not usually needed for people with early melanoma.

You may also have heard about more recent targeted treatments for cancer including for melanoma, treatments such as Keytruda, Opdivo and Yervoy. These immunotherapy drugs are used for people with advanced (or stage III and IV) melanoma. Because you have early melanoma, these drugs won't be part of your treatment plan.

Prognosis

One of the scariest things that people diagnosed with any sort of cancer think about is their prognosis; what does the future hold for me and will I die from cancer.

The prognosis for most people whose melanomas are diagnosed early is very good. As someone with early melanoma, your cancer has been diagnosed and treated before it had a chance to spread to other parts of your body. Your personal prognosis will depend on the type and stage of your melanoma, your age and general health and how well you respond to treatment.

Once your doctor has been sent the pathologist's report, you can talk about your prognosis with all the most important information in front of you.

Irrespective of what your prognosis is, you may want to speak with a counsellor who has experience with helping cancer patients. Remember that Melanoma New Zealand can provide support for you and each DHB has its own support services (psychology and social work) available. You will have a Clinical Nurse Specialist on your team, and you could also speak with them.

ARE CLINICAL TRIALS FOR YOU?

You may have heard about clinical trials and want to know if they are an option you should consider. Clinical trials test new treatments or new combinations of existing treatments, and can involve medications or surgical interventions. The goal is to achieve optimal treatments and outcomes for cancer.

Because you have early melanoma, and surgical treatment is standard, you are unlikely to be eligible for clinical trials.

However, there is a tissue bank to which you can donate the tissue removed during surgery after it has been used for diagnostic purposes. Tissue donation is enormously important in the fight against cancer and it is a simple process.

If you live in the Auckland region, with your consent and after the tissue has been used for diagnostic work, it can be donated to Auckland Regional Tissue Bank — Te Ira Kāwai. The tissue can then be made available to ethically approved research projects. Talk to your CNS or go to the website at www.tissuebank.co.nz for more information.



COPING WITH SIDE-EFFECTS

All medical treatments have side-effects and adverse events associated with them. Your experience will vary, as treatment tends to have different effects on different people even when certain side-effects are very common across all patients.

While some side-effects will be expected with your treatment you should make sure to find out from your doctors or clinical nurse specialist (CNS) what you can expect, which side-effects are common, how you can alleviate them or cope with them and when you should talk to your doctor or CNS. If you experience any symptom that is unexpected, unusually persistent or unresponsive to efforts to alleviate it, or that causes you significant discomfort, pain or debilitation, you should contact your CNS or doctor as soon as possible so that a serious adverse reaction can be ruled out, or dealt with. There are some side-effects that you should not try to manage on your own and should report them immediately to your CNS. If you are unsure what symptoms should be reported immediately, discuss this with your team and report anything you are unsure about.



Fortunately, because most early melanoma patients only have surgery, side-effects are limited. There may be pain and discomfort as you recover from surgery, and coping with changes in your appearance, depending on where your surgery site is and how extensive the scars are. Your CNS will give you information about the surgical procedure(s) prior to surgery. After surgery, if you have any

ongoing symptoms such as pain, discomfort, signs of infection or swelling in the local area and on any limb, contact your CNS.

Pain

While you heal from surgery, you may experience pain and discomfort at the site of your surgery and the skin donor site if you have had a skin graft. If you have skin flap surgery you may also experience inflammation and reduced mobility while the wounds heal. Your doctor may refer you to a physiotherapist to help with this.

Your doctor or nurse will advise you on pain management and this will depend on the severity of your pain, how often you experience pain and what is causing it. If you experience increased pain you should contact your doctor or CNS.

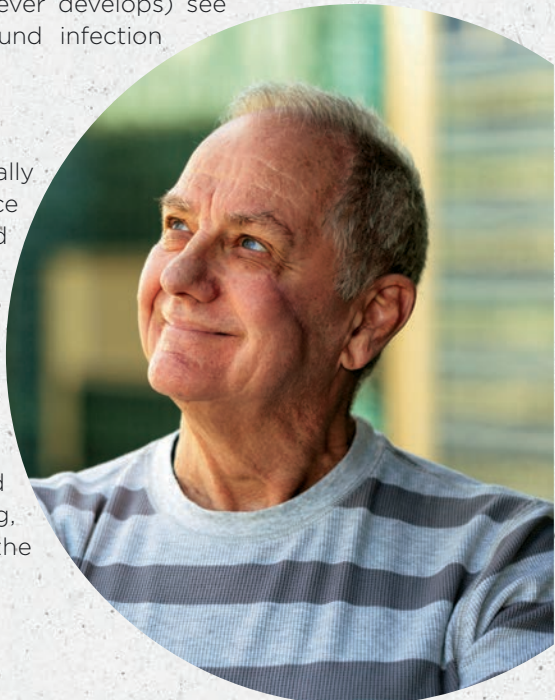
Infection

It is possible that you will develop an infection in your wound. Sometimes there is nothing you can do to avoid a wound infection, but it is important to wash your hands regularly and maintain good personal hygiene. Keep your wound clean and covered with a dry wound dressing. If you experience any signs of infection (if redness or increased redness develops around your wound, pus or fluid leaks from the wound, there is increased pain or tenderness or swelling, warmth/heat at the surgical site or a fever develops) see your doctor as soon as possible. Wound infection can increase scarring.

Scarring

You will have a scar after surgery, and initially this will look red and raw. The appearance of your scar will improve over time and fade. Everyone scars differently and how well you heal and how obvious the scar is depends on your skin type, any wound infections and complications, and how extensive the surgery was.

You can moisturise with creams and ointments, and use special wound dressings that will help minimise scarring, but they cannot prevent or remove the scar completely.



AFTER TREATMENT AND FOLLOW-UP

One of the most important aspects of your life after treatment for early melanoma is ongoing skin checks. While it is important for everyone to check their skin for changes that may indicate melanoma or other types of skin cancer, it is especially important for anyone who has already had a melanoma diagnosis.

What Happens at Follow-Up?

Immediately after treatment you will have a follow-up appointment at which your doctor or CNS will check your scar and the surrounding tissue, and your lymph nodes. You will also be checked for any signs of new melanomas. The frequency of these visits can depend on risk factors and results of your initial treatments and investigations. Most recurrences are known to take place within the first two years after diagnosis, but can happen at any point in life.

Follow-up appointments are designed to detect recurrences of your cancer as early as possible, whether that is a new primary melanoma or maybe a distant melanoma or metastases. Just as is the case with your first melanoma, the earlier recurrences are found the better your prognosis.

After you have had one melanoma, you are at higher risk for other skin cancers. A second invasive melanoma has been reported in 2 to 8% of melanoma patients, and a new melanoma *in situ* has been reported in more than 20% of melanoma patients.

Experience has shown that patients themselves are most likely to detect their own recurrence, so it is important for you to undertake regular self-skin examinations.

Looking After Yourself and Being SunSmart



SUNSMART

Most skin cancers are linked to a history of exposure to UV radiation and/or a history of sunburns; your exposure is affected by the time of the day, time of year, cloud cover, altitude and sun reflection, including from snow or water. Even though SunSmart messages are given to all New Zealanders, it is especially important for people who have had melanoma, to protect themselves from the sun: slip, slop, slap and wrap!

Slip on a shirt with long sleeves. Fabrics with a tighter weave and darker colours will give you better protection from the sun.

Slip into the shade of an umbrella or a leafy tree. Plan your outdoor activities for earlier or later in the day when the sun's UV levels are lower. Stay out of the sun during the peak UV radiation time, usually between 11am and 3pm.

Slop on sunscreen – broad-spectrum, water resistant sunscreen of at least SPF 30. It is important that you apply sunscreen 20 minutes before going outside – it takes time to be absorbed and create a protective barrier – and reapply every two hours and especially after being in water or sweating.

Slap on a hat with a wide brim or a cap with flaps.

Wear close fitting, **wrap around sunglasses** in strong sunlight.

Never use a sun lamp or sunbed.

There are tools that can help you avoid excess sun exposure that might damage your skin by letting you know about the UV status where you are and at specific times of the day. The Sun Protection Alert can be found at www.sunsmart.org.nz/sun-protection-alert and it tells you the time each day that you need to protect your skin and eyes.

You can also download a free app for your smartphone: **uv2Day** from Google Play store or iPhone app store. The app provides forecasts of the UV Index (UVI) – with and without cloud effects – throughout the day in the New Zealand, Australia, South Pacific region, including Antarctica. The app is useful for planning activities to optimise sun exposure throughout the year.

Another way to find out when you are at risk of excess sun exposure is NIWA's daily UVI forecast for specific places in New Zealand, including the ski fields. It can be found online at:

www.niwa.co.nz/our-services/online-services/uv-and-ozone/forecasts.

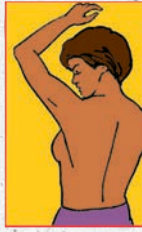
Self Skin Checks

You should do self skin checks often enough to become a habit – about every one to three months. After you have done it a few times, it shouldn't take more than a few minutes, but you will probably need someone else to check your back and the backs of your legs, so ask your partner or a good friend to help you. The illustrations on the opposite page will help you determine how to do a self skin check.

DermNet NZ and Melanoma New Zealand have a great self skin check video to help you at www.dermnetnz.org/topics/self-skin-examination-video/



Examine your body front and back in a mirror, on the left and right sides with arms raised.



Bend your elbows and look carefully at your forearms, the back of your upper arms and your palms.



Check the back of your legs and your feet as well as the spaces between your toes and the soles of your feet.

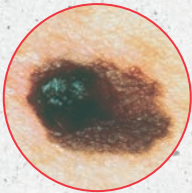


Examine the back of your neck and part your hair to check your scalp with a hand mirror; use a comb.

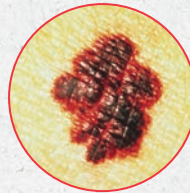


Finally, use the hand mirror to check your back and buttocks.

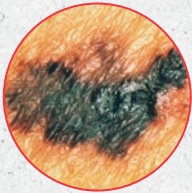
You need to be familiar with what normal skin looks like for you, and be aware of changes. We recommend that you follow the 'Ugly Duckling' rule. The idea behind the Ugly Duckling rule is that you compare your moles with each other. If any mole stands out or looks different from that of nearby moles, it is the ugly duckling, and you should contact your doctor to get an expert opinion. Look for:



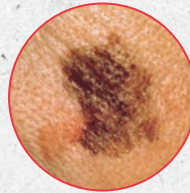
Asymmetry – one half is different from the other



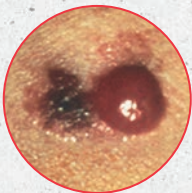
Border Irregularity – the edges are notched, uneven or blurred



Colour that is uneven – shades of brown, tan and black, pink, white or blue



Different from other moles or lesions ('ugly duckling')



Evolving or changing – in size, elevation, or is new.

Also, if you have a spot that

- itches or hurts,
- crusts or scabs,
- ulcerates or bleeds,
- fails to heal within three weeks.

Note: The images used are indicative only, as colours and details may vary depending on your screen or print copy.

COMPLEMENTARY THERAPIES

Complementary therapies – sometimes called complementary and alternative therapies (CAM) or holistic therapies – are increasingly being used by cancer patients. These are therapies that sit outside conventional medicine and range from herbal medicine to massage, yoga and mindfulness.

It is not in the scope of this book to recommend an alternative approach to treatment of melanoma, and Melanoma New Zealand recommends conventional medical treatment for melanoma. However, complementary therapies increasingly have a role in helping people cope with and manage the symptoms and effects of their cancer, to lessen or cope with any side-effects of treatment they are having, to boost their overall health and immunity and to improve their quality of life.

In this sense, the emphasis is on “complementary”; therapies you may choose to use alongside your conventional treatment. If you are considering taking supplements or herbal medicines you should tell your health team.

Increasingly, CAM practitioners have advanced qualifications, much experience working with cancer patients, and can offer useful treatment programmes that will complement your conventional treatment and improve your well-being and quality of life.



Just as not all conventional medicine works all the time for everyone, not all complementary therapies work all the time for everyone. You will need to do

your own research, get advice from a registered complementary practitioner and find things that work for your particular circumstances and needs. Many hospitals and doctors offer or recommend complementary therapies alongside your conventional care.



You may want to consider:

- Nutritional advice to keep your body as healthy as possible and help it become stronger and more resilient.
- Aromatherapy, massage, Reiki, reflexology, mindfulness/meditation, visualisation or guided imagery techniques to help you cope with pain, stress, anxiety and sleep concerns.
- Art and music therapy for helping you to express your feelings and coping with anxiety.
- Traditional Māori healing such as rongoā Māori, romiromi or mirimiri – customary remedies based on native plants, massage therapy and spiritual healing.



There is no need to be nervous about letting your health team know that you are considering, or wish to use complementary therapies to enhance your health and well-being.



TALKING TO YOUR FAMILY/WHANAU

Telling family/whānau and friends about their diagnosis is something that many people with cancer find very difficult. How you approach this is very individual and will depend if you have children to tell, and how old they are, and the sorts of relationships within your family/whānau and circle of friends.



You may find it hard to talk about your diagnosis and prognosis. Sometimes your friends and family/whānau may not know what to say to you or how to support you. They may have difficulty with their own feelings, which may be similar to your own: sadness, anger, fear, guilt and uncertainty. Some cancer patients find that, not only are they coping with their own feelings about their diagnosis, treatment and life with cancer, but trying to manage the feelings and concerns of those closest to them as well.

Support for Family/Whanau

Most of this booklet is about and you your needs as you undertake treatment for early melanoma. However, many people find that their families/whānau need support too.

As a first step, you could give your family/whānau members this booklet to read. This would help them understand some of the things that you face from your diagnosis and treatment.



THE IMPACT OF MELANOMA ON YOUR LIFE

It is normal for people receiving a cancer diagnosis to experience a range of emotions: fear, anger, guilt and blame; feeling alone; and concern for how other people in your life will cope with your diagnosis. Cancer patients commonly report disbelief that this is happening to them, sadness, despair and a sense of feeling overwhelmed.

It is important to work through all your emotions in your own time and at a pace that feels right for you. However, help is available if you need it.

Coping With Diagnosis

Every person has a different way of coping with their diagnosis. Irrespective of the initial feelings that you have about your diagnosis, many people find that over time these emotions become easier to cope with. However, at the beginning it can be hard to think of anything but the cancer, and you may feel like your diagnosis and treatment have taken over your life.

Some people find that the best thing to do is carry on with life as normally as they can, continuing with as many of their normal activities as possible, staying in touch with family/whānau and friends and keeping as normal a routine as treatment allows. However, some people decide - or need - to reprioritise their lives.

This may mean spending more time with family/whānau or friends, changing their lifestyle, or taking up a relaxing or self-focussed hobby or activity, a new physical activity that makes allowances for changes to their bodies and capabilities, or perhaps a much longed for holiday or trip.



Allow yourself time to adjust to this new life or period in your life, in which your body is undergoing changes. Treat yourself with compassion and kindness. It may be that this is the first time in your adult life when you have put yourself first; accept that for you this is the right thing to do, at least for now.

Talk with other cancer patients, people who have been through or are living with the same issues and concerns that you have. As well as learning new ways of coping and living with your disease, this will help you to feel less alone.

Many people who have had cancer report that humour has many positive benefits. While there will no doubt be many times that laughter has never seemed so far away or less appropriate, it has many positive benefits on both the mind and body and can help you relax at a difficult time.

Ask for and accept help, even if it is just with simple things. Treatment may be energy-sapping and you may not be able to keep up a previous busy schedule, so ask friends and family/whānau to support you and help out so that you can put your energy into healing and staying well.

How You May Feel And React

Common reactions include fear and anxiety, anger, avoidance, guilt and blame, sadness, feeling alone, and feeling overwhelmed. You may have body image concerns, and possibly anxiety or depression. It is important that you have ways to cope with negative emotions so you can enjoy your life as much as possible.

Physical Changes

Having cancer, in particular if the treatment results in changes to how your body looks or functions, can lead you to experience negative feelings about your body image. These might include negative feelings associated with your looks, such as changes in your skin quality and appearance; and impacts on your sex life, including libido and your sense of desirability.

Changes in your appearance, such as having a melanoma removed from a visible part of your body, scarring or skin grafts, may be hard to come to terms with. Some people experience feelings of embarrassment, and this affects the way that they feel about themselves and how their body looks.



Things that may help you to cope with feelings associated with melanoma and its treatment include

- talking to supportive friends, family/whānau and health professionals, or a trained counsellor;
- gathering information from health professionals to understand your melanoma better;
- taking care of yourself by eating and sleeping well;
- doing little things that might make you feel better (e.g. having a bath, dressing nicely or wearing make-up);
- faith, prayer or spirituality, art or music therapy, or yoga;
- planning enjoyable activities;
- trying to keep doing normal activities;
- getting involved in a support group, or meeting other people who are also living with cancer.
- joining the closed Facebook group Melanoma Support New Zealand. Because this is a closed group, your posts are only visible to other members of the group.

If you are struggling to come to terms with the changes in the appearance or functionality of your body, talk with your health team or your clinical nurse specialist, your GP or a trained counsellor.

Anxiety or Depression

It is normal to feel sad, worried or fearful about advanced melanoma, treatment and your prognosis. But if your feelings of sadness and fear are very strong or persistent, and don't resolve within a couple of weeks you may have depression and need more help to overcome this; talk to your care team who can help you find the support you need.

STRESS MANAGEMENT

Dealing with cancer can be enormously stressful and managing stress effectively is an important aspect of caring for yourself. We know that stress can have negative impacts on the immune system, and when dealing with cancer and having treatment you need to have your immune system working as well as possible. However, there are things you can do for yourself to help manage and reduce stress.

Ask for help from family/whānau and friends, and colleagues if you can. Many people will be happy to step in and help where they can, so think about particular tasks you need help with beforehand, and before you desperately need help.

Nutrition and Physical Activity

There are things that you can do that will not only improve your health but reduce your stress through feeling more relaxed and feeling less anxious. It is important to eat well, exercise and spend time outdoors.

It is important to ask your health team about when it is safe to resume or take up new physical activities and exercise, especially if this is water based. For example, some grafts and wounds have non-dissolving stitches.



SUPPORT FROM MELANOMA NEW ZEALAND

Melanoma New Zealand offers a range of support to people with melanoma and their families, carers and supporters. Our Melanoma Information Advisor is ready to help you interpret information and clarify your understanding of melanoma. While your best source of information about your situation will always be your own clinical team, the Melanoma Information Advisor is happy to listen to you, explain terminology or concepts, and provide support, and contacts for other services.

You can contact the Melanoma Information Advisor on freephone 0800 463 526 or at admin@melanoma.org.nz.

RESOURCES

General Melanoma Information

Melanoma New Zealand	www.melanoma.org.nz
Cancer Society of New Zealand	www.cancernz.org.nz
New Zealand Dermatological Society (DermNet)	www.nzdsi.org/index.aspx
Melanoma Unit	www.nzmu.co.nz/

Support

Melanoma New Zealand	www.melanoma.org.nz
Cancer Society of New Zealand	www.cancernz.org.nz
Northern Cancer Network	www.northerncancernetwork.org.nz
Midland Cancer Network	www.midlandcancernetwork.org.nz
Central Cancer Network	www.centralcancernetwork.org.nz
Southern Cancer Network	www.sialliance.health.nz/our-priorities/southern-cancer-network

Melanoma Treatment

Clinical Practice Guidelines for the Management of Melanoma in Australia & NZ
www.health.govt.nz/system/files/documents/publications/melanoma-guideline-nov08-v2.pdf

Standards of Service Provision for Melanoma Patients in New Zealand
<http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/faster-cancer-treatment-programme/national-tumour-standards>

(These are updated on a regular basis so this link may not take you to the most current standards.)

Supporting Children

Skylight www.skylight.org.nz
Skylight is a New Zealand not for profit trust that enables children, young people, their family/whānau and friends to navigate through times of trauma, loss and grief.

RipRap www.riprap.org.uk
A website especially for teenagers who have a parent with cancer.

Cancer Care www.cancercare.org
Helping children when a family member has cancer: www.cancercare.org/publications/22-helping_children_when_a_family_member_has_cancer

Health and Wellbeing

Healthline

0800 611 116 for free, for advice from trained registered nurses

Gawler Foundation

<https://gawler.org>

Health Navigator

www.everybody.co.nz

Community Services

CanTeen

www.canteen.org.nz

People aged between 13 and 24 who have been diagnosed with melanoma or any other cancer can contact CanTeen for support. Call 0800 226 8336 or visit the Canteen website.

Look Good, Feel Better

www.lgfb.co.nz

Look Good Feel Better is a free service for those undergoing treatment for any form of cancer. Free makeover workshops are available to restore appearance confidence during and after treatment. Ph 0800 865 432 or visit the Look Good, Feel Better website.

Pinc and Steel Cancer Rehabilitation Programme www.pincandsteel.com

Offer a range of exercise and physiotherapy programmes, which are designed to help people of all ages recovering from any type of cancer surgery or cancer treatments.

International

Melanoma Institute Australia

www.melanoma.org.au

Melanoma Research Foundation

www.melanoma.org

Melanoma International Foundation

www.melanomainternational.org

GLOSSARY

Adverse event An adverse event is an untoward medical occurrence or injury in a patient as a result of treatment received. An adverse event could be caused by a procedure, such as surgery, or medication/drugs.

Alternative therapies Therapies or treatments that are outside conventional medical practices, also referred to as complementary and alternative (CAM), natural or holistic therapies.

Anaesthetic A drug that causes numbness or loss of feeling in an area (local), a region (spinal or epidural) or all (general) of the body.

Analgesia or analgesic Painkillers; prescription or over the counter drugs.

Benign Not cancer – does not invade nearby tissues or spread to other parts of the body.

Biopsy The removal of a sample of tissue for examination under a microscope to check for cancer cells.

Breslow Thickness The thickness in millimeters between the upper layer of the epidermis and the deepest point of tumour penetration. Breslow thickness is related to the five-year survival rate after surgical removal of the tumour.

Clinical Nurse Specialist (also melanoma clinical nurse specialist) A specialist nurse, who provides support to you and your family/whānau and can help to co-ordinate your care.

Clinical trials Medical research studies conducted with volunteers. Each study is designed to answer scientific questions and to find better ways to prevent or treat cancer.

Complementary therapies Treatments or therapies that are used alongside conventional medical treatment and often used by patients to improve quality of life or to reduce the impact of side-effects from conventional treatment.

Dermatologist A doctor who specialises in diagnosing and treating skin problems.

Donor site The place on your body where skin is taken from in a skin graft to replace tissue removed in wide excision surgery.

Excision margin The amount of healthy skin clear of cancer cells from around your melanoma that is removed in a wide local excision. The size of the excision margin depends on the Breslow thickness of your melanoma.

Grafted area The site of your wide excision where donor skin is moved to, to replace tissue removed in wide excision surgery.

Lymph The almost colourless fluid that travels through the lymphatic system and carries cells that help fight infection and disease.

Lymph nodes Small, bean-shaped structures along the network of lymphatic vessels. They store special cells that can trap bacteria or cancer cells travelling in lymph. Clusters of lymph nodes are found in the armpits, groin, neck, chest, and abdomen.

Lymphatic system The system of structures that move lymph around the body.

Lymphoedema A condition in which excess fluid collects in tissue and causes swelling. It may occur in the arm or leg after lymph vessels or lymph nodes in the underarm or groin are removed.

Malignant Cancerous; can invade nearby tissue and spread to other parts of the body.

Melanin A skin pigment (substance that gives the skin its colour). Dark-skinned people have more melanin than light-skinned people.

Melanocytes Cells in the skin that produce and contain the melanin.

Pathologist A doctor who identifies diseases by studying cells and tissues under a microscope.

Plastic surgeon A surgeon who specialises in reconstructive, skin or cosmetic surgery.

Prognosis The probable outcome or course of a disease; the chance of recovery.

Regression Regression, describes an area where it appears there have been melanoma cells, but these have been destroyed by the immune system and replaced with inflammation or scar tissue. When regression is present, the total size of the melanoma is hard to characterise because it is difficult to tell how extensive it was before the regression occurred.

Satellitosis Satellite lesions (also called micro satellites) are areas of melanoma located more than 0.05 mm, but less than 2cm, from the primary lesion. Satellites are described as being present or absent. These are also reflected in the staging.

Sentinel Nodes The first few lymph nodes in the lymphatic system into which a tumour drains and to which tumour cells are most likely to spread.

Skin flap A thicker layer of skin than a skin graft, used to replace tissue removed in wide local excision surgery.

Skin graft Skin that is moved from one part of the body to another.

Tumour An abnormal mass of tissue.

Wide Excision Wide excision is a surgical procedure to remove the tumour with a margin of normal, healthy tissue. This procedure is commonly performed on skin cancers, including melanoma, and in breast cancer surgery, but can be used on any area of the body.

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Understanding Early Melanoma

More than anything else, we want you to know that you are not alone; that there is help and support for you both through Melanoma New Zealand, your medical team and district health board, and other organisations whose role is to help you and your family through your cancer diagnosis and treatment, and life beyond.

Receiving a diagnosis of melanoma can be frightening. You'll probably have many questions about melanoma and what will happen next. This booklet is designed to answer some of the questions you may have about your diagnosis of and treatment for early melanoma and life afterwards, including:

- what melanoma is
- diagnosis
- what you should ask
- treatment options
- your medical team and how they can help
- complementary therapies
- coping with side-effects
- after treatment follow-up and staying SunSmart



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