

Understanding Melanoma

A guide for people with cancer, their families and friends



For information & support, call **13 11 20**

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Check the publication date above to ensure this copy is up to date.

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

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Cancer Council is Australia's peak non-government cancer control organisation. Through the 8 state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.



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About this booklet

This booklet has been prepared to help you understand more about melanoma, a type of skin cancer. Other types of skin cancer include basal cell carcinoma (BCC) and squamous cell carcinoma (SCC), which are often called non-melanoma skin cancers or keratinocyte cancers. For information about non-melanoma skin cancers, see our *Understanding Skin Cancer* booklet.

Many people feel shocked and upset when told they have melanoma. We hope this booklet will help you, your family and friends understand how melanoma is diagnosed and treated. We also include information about support services. We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 51).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 52). You may also like to pass this booklet to family and friends for their information.

How this booklet was developed – This information was developed with help from a range of health professionals and people affected by melanoma. It is based on Australian clinical practice guidelines.¹



If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).

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Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Personal story

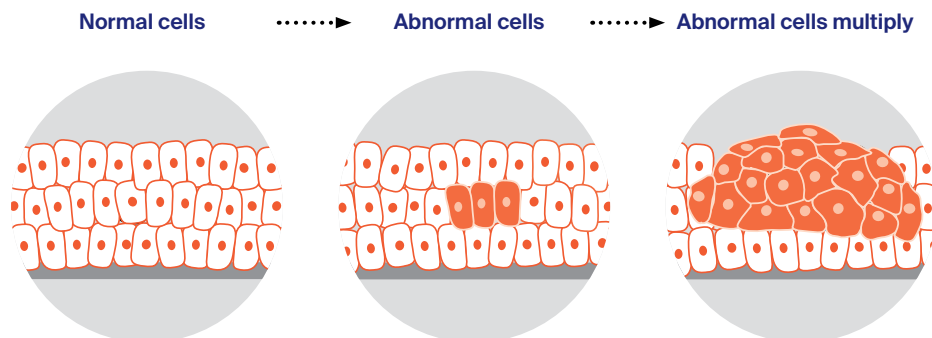
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. These abnormal cells may turn into cancer.

In solid cancers, such as melanoma, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

How cancer starts

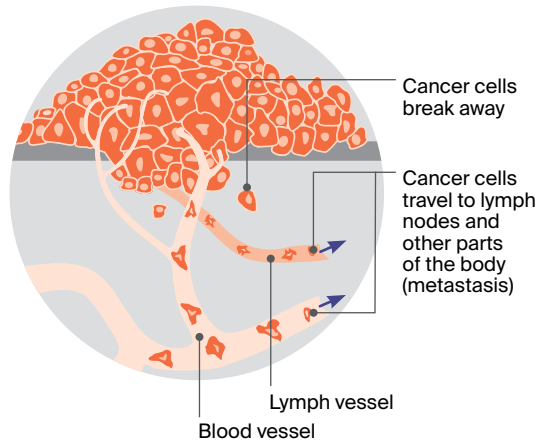
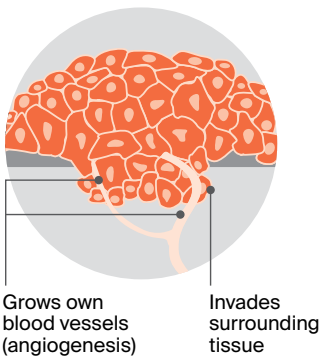


Not all tumours are cancers. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops in a tissue or organ is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, melanoma that has spread to the brain is called metastatic melanoma, even though the main symptoms may be coming from the brain.

How cancer spreads

Malignant cancer





The skin

The skin is the largest organ of the body. It acts as a barrier to protect the body from injury, control body temperature and prevent loss of body fluids. The 2 main layers of the skin are the epidermis and the dermis. Below these is a layer of fatty tissue known as the hypodermis.

Epidermis

The epidermis is the top, outer layer of the skin. It is made up of several sublayers that work together to continually rebuild the surface of the skin. The main sublayers are the basal cell layer and the squamous cell layer.

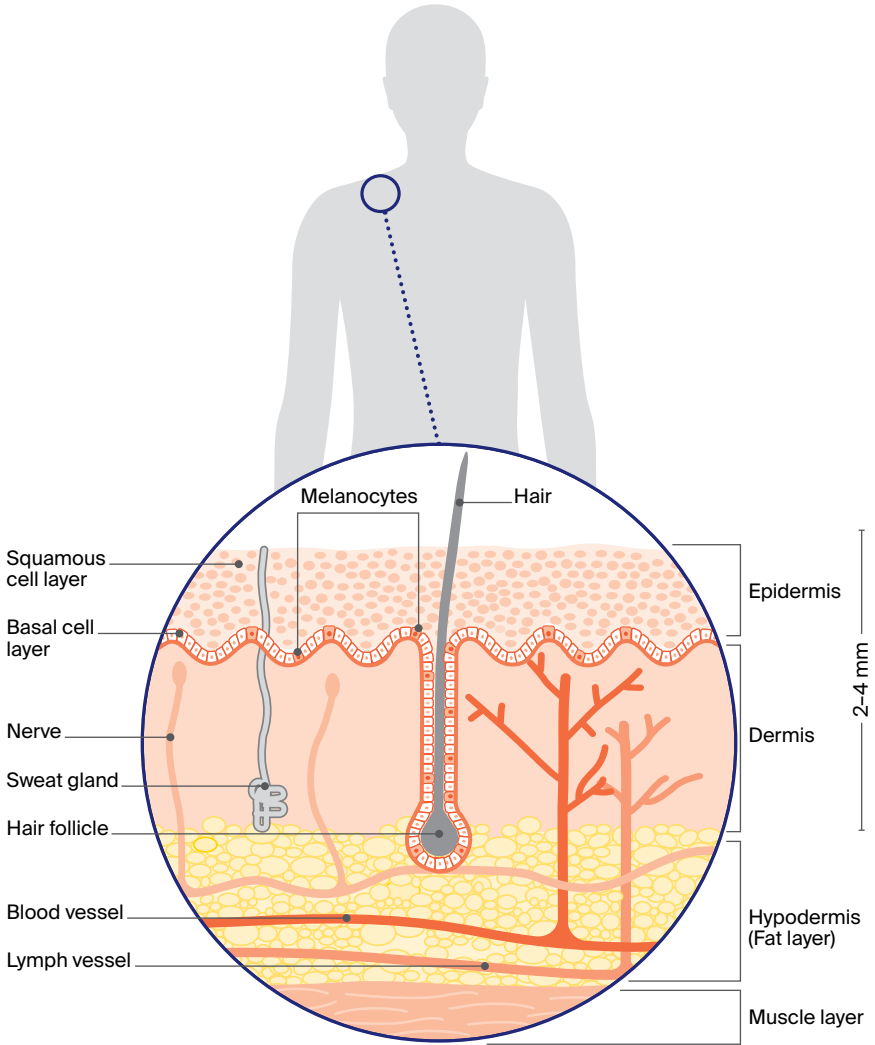
Basal cell layer – This is the lowest layer of the epidermis. It contains basal cells and cells called melanocytes. The melanocyte cells produce a dark pigment called melanin, which gives skin its colour. When skin is exposed to ultraviolet (UV) radiation, melanocytes make melanin to try to protect the skin from getting burnt. This is what causes skin to tan. When melanocytes cluster together they form non-cancerous spots on the skin called moles or naevi.

Squamous cell layer – This sits above the basal cell layer. Basal cells that have matured move up into the squamous cell layer. Here they are known as squamous cells or keratinocyte cells. Squamous cells are the main type of cell found in the epidermis.

Dermis

This layer of the skin sits below the epidermis. The dermis is made up of fibrous tissue and contains the roots of hairs (follicles), sweat glands, blood vessels, lymph vessels and nerves.

The layers of the skin



Key questions

Q: What is melanoma?

A: Melanoma is a type of skin cancer. It develops in the skin cells called melanocytes (see page 6).

Melanoma most often develops in areas that have been exposed to the sun. It can also start in areas that don't receive much sun, such as the eye (uveal or ocular melanoma); nasal passages, mouth and genitals (mucosal melanoma); and the soles of the feet or palms of the hands, and under the nails (acral melanoma).

Other types of skin cancer include basal cell carcinoma (BCC) and squamous cell carcinoma (SCC). These are known as non-melanoma skin cancers or keratinocyte cancers, and they are far more common than melanoma. However, melanoma is considered the most serious form of skin cancer because it is more likely to spread to other parts of the body, especially if not found early. The earlier melanoma is found, the more successful treatment is likely to be.

Q: How common is melanoma?





A: Australia and New Zealand have the highest rates of melanoma in the world. Melanoma is the second most common cancer in men and the third most common cancer in women (excluding non-melanoma skin cancers).² Every year in Australia, about 17,800 people are diagnosed with melanoma that has spread into the dermis (known as invasive melanoma).² About 27,500 people are diagnosed each year with melanoma that is confined to the epidermis (melanoma in situ).³

Q: What are the signs and symptoms?

A: How melanoma looks can vary greatly. If you have lots of moles, a melanoma usually stands out and looks different from other moles. The first sign of melanoma is often a new spot or a change in an existing mole.




Signs of melanoma

ABCD signs

Asymmetry	Are the halves of each spot different?	
Border	Are the edges uneven, scalloped or notched?	
Colour	Are there differing shades and colour patches?	
Diameter	Is the spot greater than 6 mm across, or is it smaller than 6 mm but growing larger?	

EFG signs

Some types of melanoma, such as nodular and desmoplastic melanomas (see page 12), don't fit the ABCD guidelines.

Elevated	Is it raised?	
Firm	Is it firm to touch?	
Growing	Is it growing quickly?	



For an overview of what to expect at every stage of your cancer care, visit cancer.org.au/cancercareguides/melanoma. This is a short guide to what is recommended, from diagnosis to treatment and beyond.

Q: How do I spot a melanoma?

A: New moles mostly appear during childhood and through to the 30s and 40s. However, adults of any age can develop new or changing spots. It is important to get to know your skin and check it regularly.

In a room with good light, undress completely and use a full-length mirror to check your whole body. For areas that are hard to see, use a handheld mirror or ask someone to help. It is also a good idea to take a photograph of your moles and spots so that you can compare them to an older image if you notice one has changed.

Look for spots that are new, different from other spots, or raised, firm and growing (see previous page). Even if your doctor has said a spot is benign in the past, check for any changes in shape, size or colour. If you notice a new or changing spot, get it checked as soon as possible by your doctor.

Q: What causes melanoma?

A: Exposure to ultraviolet (UV) radiation is the cause of most types of skin cancer. If unprotected skin is exposed to the sun when the UV index is 3 or above or to other UV radiation, the structure and behaviour of the cells can change. This can permanently damage the skin, and the damage builds up every time a person spends time unprotected in the sun.

UV radiation most often comes from the sun, but it can also come from artificial sources such as solariums (also known as tanning beds or sun lamps). Solariums are now banned for commercial use in Australia because research shows that people who use solariums have a much greater risk of developing melanoma.

Q: Who is at risk?

A: Anyone can develop melanoma. The risk is higher for people who have:

- unprotected exposure to UV radiation when the UV index is 3 or above, particularly a pattern of short, intense periods of sun exposure and sunburn, such as on weekends and holidays
- lots of moles (naevi), especially if the moles have an irregular shape and uneven colour
- pale or freckled skin, especially if it burns easily and doesn't tan
- fair or red hair, and blue or green eyes
- a previous melanoma or other type of skin cancer
- a strong family history of melanoma (see below)
- a weakened immune system from using immunosuppressive medicines for a long time.

Family history of melanoma

Sometimes the risk of melanoma runs in families. Often, this is because family members have a similar skin type or a similar pattern of sun exposure in childhood.

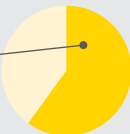
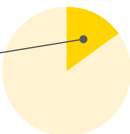
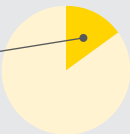
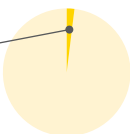
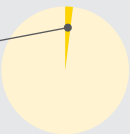
About 2% of melanomas are linked to an inherited faulty gene. You may have an inherited faulty gene if 2 or more close relatives (parent, sibling or child) have been diagnosed with melanoma, particularly if they were diagnosed with more than one melanoma, or if they were diagnosed with melanoma before the age of 40.

People with a strong family history of melanoma should use sun protection and check their skin carefully for new moles or skin spots. From their early 20s, they should consider having a professional skin check by a doctor. This may be every year. Discuss the frequency with your doctor.

If you are concerned about your family risk factors, talk to your doctor about referral to a family cancer clinic. Visit genetics.edu.au to find a family cancer clinic near you. To learn more, call Cancer Council 13 11 20.

What are the main types of melanoma?

Melanoma of the skin is known as cutaneous melanoma. The main subtypes of cutaneous melanoma are shown in this table. Some rarer types of melanoma start in other parts of the body. Mucosal melanoma can start in the tissues in the mouth,

Subtype	How common?	Who gets it?
superficial spreading melanoma	55–60% of melanomas 	most common type of melanoma in people under 40, but can occur at any age
nodular melanoma	10–15% of melanomas 	most commonly found in people over 65
lentigo maligna melanoma	10–15% of melanomas 	most people with this subtype are over 40
acral lentiginous melanoma	1–2% of melanomas 	mostly affects people over 40 with dark skin such as those of African, Asian and Hispanic backgrounds
desmoplastic melanoma	1–2% of melanomas 	mostly affects people over 60

anus, urethra, vagina or nasal passages. Ocular melanoma can start inside the eye. Melanoma can also start in the central nervous system. See our *Understanding Ocular Melanoma* fact sheet or call 13 11 20 for information about rarer types of melanoma.

What does it look like?	Where is it found?	How does it grow?
can start as a new brown or black spot that grows on the skin, or as an existing spot, freckle or mole that changes size, colour or shape	can develop on any part of the body but especially the area between the shoulders and hip (trunk)	often grows slowly and becomes more dangerous when it invades the lower layer of the skin (dermis)
usually appears as a round, raised lump (nodule) on the skin that is pink, red, brown or black and feels firm to touch; may develop a crusty surface that bleeds easily	usually found on sun-damaged skin	fast-growing form of melanoma, spreading quickly into the lower layer of the skin (dermis)
begins as an enlarging pigmented spot	mostly found on sun-damaged skin on the face, ears, neck or head	may grow slowly and superficially over many years before it grows deeper into the skin
often appears as a colourless or lightly coloured area, may be mistaken for a stain, bruise or unusual wart; in the nails, can look like a long streak of pigment	most commonly found on the palms of the hands, on the soles of the feet, or under the fingernails or toenails	tends to grow slowly until it invades the lower layer of the skin (dermis)
starts as a firm, growing lump, often the same colour as your skin; may be mistaken for a scar and can be difficult to diagnose	mostly found on sun-damaged skin on the head or neck, including the lips, nose and ears	tends to be slower to spread than other subtypes, but often diagnosed later; sometimes can invade or spread via nerves

Q: Which health professionals will I see?

A: You will probably start by seeing your general practitioner (GP).

If a GP diagnoses or suspects melanoma, they may remove the spot (excision biopsy, see page 16) or refer you to another doctor, such as a dermatologist or surgeon, for the biopsy. A pathologist will examine the biopsy specimen to confirm a melanoma diagnosis.

Your doctors can arrange further tests and suggest ways to treat the melanoma. These options may be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. Some people choose to see a doctor at a skin cancer clinic. These are usually staffed by GPs with a specific interest in skin cancer.

Visiting a melanoma unit

Management and treatment for advanced melanoma is complex.

People with a melanoma thicker than 1 mm or less than 1 mm but with high-risk features, or a melanoma that has spread, may benefit from having treatment in a cancer treatment centre that has doctors who specialise in the treatment of advanced melanoma. These are located at hospitals in major cities around Australia. You will be able to see a range of health professionals who specialise in different aspects of your care.

To find a multidisciplinary melanoma unit near you, check with your doctor or call Cancer Council 13 11 20.

Melanoma Patients Australia also provides a list of major melanoma units at melanomapatients.org.au/treatment/treatment-centres.

Most people with early melanoma do not need to go to one of these multidisciplinary melanoma units.

Health professionals you may see

GP	checks skin for suspicious spots, may remove potential skin cancers and refer you to specialists
dermatologist	diagnoses, treats and manages skin conditions, including skin cancer
general surgeon	performs surgery to remove early melanoma and lymph nodes, and to reconstruct the skin
reconstructive (plastic) surgeon	performs surgery that restores, repairs or reconstructs the body's appearance and function; may also remove lymph nodes
surgical oncologist	performs surgery to remove melanoma and conducts more complex surgery on the lymph nodes and other organs; can be a general surgeon or a reconstructive surgeon
medical oncologist	treats melanoma with drug therapies such as targeted therapy and immunotherapy
radiation oncologist	plans and delivers radiation therapy
cancer care coordinator	coordinates care, liaises with MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
counsellor, social worker, psychologist	help you manage your emotional response to diagnosis and treatment
physiotherapist, occupational therapist	assist with physical and practical issues, including restoring movement and mobility after treatment and recommending aids and equipment
palliative care specialist and nurse	work closely with the GP and cancer team to help control symptoms and maintain quality of life

Diagnosis

The first step in diagnosing a melanoma is a close examination of the spot. If the spot looks suspicious, the doctor will remove it so it can be checked in a laboratory. In some cases, further tests will be arranged.

Physical examination

If you notice any changed or suspicious spots, your doctor will look carefully at your skin. The doctor will ask if you or your family have a history of melanoma. The doctor will consider the signs known as the ABCD and EFG guidelines (see page 9) and examine the spot more closely with dermoscopy, which involves using a handheld magnifying instrument called a dermatoscope.

People with a high risk of developing melanoma may have photos taken of their skin to make it easier to look for changes over time. This is known as total body photography.

Removing the spot (excision biopsy)

If the doctor suspects that a spot on your skin may be melanoma, the whole spot is removed (excision biopsy). While this is the preferred type of biopsy to remove the spot, other types may be used.

An excision biopsy is generally a simple procedure done in your doctor's office. Your GP may do this procedure, or you may be referred to a dermatologist or surgeon. For the procedure, you will have an injection of local anaesthetic into the area around the spot to numb the area. The doctor will use a scalpel to remove the spot and a small

amount of healthy tissue (2 mm margin) around it. It is recommended that the entire spot is removed rather than a small sample. This helps ensure an accurate diagnosis of any melanoma found. The wound will usually be closed with stitches and covered with a dressing. You'll be told how to look after the wound and dressing.

A doctor called a pathologist will examine the tissue under a microscope to work out if it contains melanoma cells. Results are usually ready within a week. For information about what the pathology results mean, see page 19.

You'll have a follow-up appointment to check the wound and remove the stitches. If a diagnosis of melanoma is confirmed, you will probably need a second operation to remove more tissue. This is called a wide local excision (see page 26).

Checking lymph nodes

Lymph nodes are part of your body's lymphatic system. This is a network of vessels, tissues and organs that helps to protect the body against disease and infection. There are large groups of lymph nodes in the neck, armpits and groin. Sometimes melanoma can travel through the lymphatic system to other parts of the body.

To work out if the melanoma has spread, your doctor will suggest tests to check the lymph nodes. Not everyone needs these tests.

Ultrasound – Used if any lymph nodes feel enlarged, see page 20.

Needle biopsy – If any lymph nodes look or feel enlarged, you will probably have a fine needle biopsy. This uses a thin needle to take

a sample of cells from the enlarged lymph node. Sometimes, a thicker sample needs to be removed (core biopsy).

The sample is examined under a microscope to see if it contains cancer cells. If cancer is found in the lymph nodes, you may be offered surgery to remove them (lymph node dissection, see pages 29–30). This may be at a specialist melanoma unit.

Sentinel lymph node biopsy – You may be offered a sentinel lymph node biopsy if the melanoma is more than 1 mm thick (Breslow thickness, see opposite) or is less than 1 mm with high-risk features. A sentinel node biopsy helps find melanoma in the lymph nodes before they become swollen.

When melanoma spreads, it first travels to particular lymph nodes. These are called the sentinel nodes. A sentinel node biopsy finds and removes them so they can be checked for melanoma cells under a microscope. If your doctor thinks you need a sentinel node biopsy, you have it at the same time as the wide local excision (see pages 26–28).

To find the sentinel lymph node, a small amount of radioactive dye is injected into the area where the initial melanoma was found. The surgeon removes any lymph nodes that take up the dye so a pathologist can check them under the microscope for cancer cells.

If cancer cells are found in a removed lymph node, you may have further tests such as CT or PET-CT scans (see page 20). The results of a sentinel lymph node biopsy can help predict the risk of melanoma spreading to other parts of the body. This information helps the multidisciplinary team plan your treatment options and decide whether you are suitable for drug therapies.

Understanding the pathology report

The report from the pathologist is a summary of information about the melanoma that helps determine the diagnosis, the stage, the recommended treatment and the expected outcome (prognosis). You can ask your doctor for a copy of the pathology report. It may include:

Breslow thickness – This is a measure of the thickness of the tumour in millimetres to its deepest point in the skin. The thicker a melanoma, the higher the risk it could return (recur) or spread to other parts of the body.

Melanomas are classified as:

- in situ – found only in the top layer of the skin (epidermis)
- thin – less than 1 mm
- intermediate – 1–4 mm
- thick – greater than 4 mm.

Ulceration – The breakdown or loss of the outer layer of skin over the tumour is known as ulceration. It is a sign the tumour is growing quickly.

Mitotic rate – Mitosis is the process by which one cell divides into two. The pathologist counts the number of actively dividing cells within a square millimetre to calculate how quickly the melanoma cells are dividing.

Clark level – This describes how many layers of skin the tumour has grown through. It is rated on a scale of 1–5, with 1 the shallowest and 5 the deepest. (On the report, the Clark level will be written in Roman numerals as I, II, III, IV or V.) The Clark level is not the same as the stage.

Margin – This is the area of normal skin around the melanoma. The report will describe how wide the margin is and whether any melanoma cells were found at the edge of the removed tissue.

Regression – This refers to inflammation or scar tissue in the melanoma, which suggests that some melanoma cells have been destroyed by the immune system. In the report, the presence of lymphocytes (immune cells) in the melanoma indicates inflammation.

Lymphovascular invasion – This means that melanoma cells have entered the lymphatic system or blood vessels.

Satellites – Small areas of melanoma found more than 0.05 mm but less than 2 cm from the primary melanoma.

Further tests

Often, only a biopsy is needed to diagnose melanoma. If pathology results show the melanoma is thicker, you will have blood tests or scans to find out more about the melanoma. You may also have these tests during treatment or as part of follow-up care after treatment finishes.

Ultrasound – The person doing the ultrasound will move a handheld device called a transducer across part of your body. The transducer sends out soundwaves that echo when they meet something solid, such as an organ or tumour. A computer turns the echoes into pictures.

CT scan – A CT (computerised tomography) scan uses x-ray beams to create detailed, cross-sectional pictures. Before the scan, you may have an injection of a liquid dye (called the contrast) to make the pictures clearer. The CT scanner is large and round like a doughnut. You will need to lie still on a table while the scanner moves around you.

MRI scan – An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to create detailed cross-sectional pictures. Before the scan, you may have an injection of a liquid dye (called the contrast) to make the pictures clearer. During the scan, you will lie on an examination table that slides into a large metal tube that is open at both ends. The noisy and narrow MRI machine makes some people feel anxious or claustrophobic. You may be offered headphones or earplugs to manage the noise, or prescribed medicines to help you relax.

PET-CT scan – A PET (positron emission tomography) scan combined with a CT scan is a specialised imaging test. You will be injected in the arm with a glucose solution containing a small amount of radioactive material. Cancer cells show up brighter on the scan because they take up more of the glucose solution than normal cells do.

Staging melanoma

The pathology report and any other test results will show whether you have melanoma and whether it has spread to other parts of the body.

This is known as staging and it helps your team recommend the most appropriate treatment for you. The melanoma will be given an overall stage of 0–4 (usually written in Roman numerals as 0, I, II, III or IV).

Stages of melanoma

stage 0 (in situ)	The melanoma is confined to the top, outer layer of the skin (epidermis).	very early or localised melanoma
stage 1	The melanoma has not moved beyond the primary site and is less than 1 mm thick with or without ulceration, or 1–2 mm thick without ulceration.	early or localised melanoma
stage 2	The melanoma has not moved beyond the primary site and is 1–2 mm thick with ulceration, or more than 4 mm thick with or without ulceration.	early or localised melanoma
stage 3	The melanoma has spread to lymph nodes near the primary site, to nearby skin or to tissues under the skin (subcutaneous).	regional melanoma
stage 4	The melanoma has spread to distant skin or subcutaneous tissues and/or other parts of the body, such as the lungs, liver, brain, bone, or distant lymph nodes.	advanced or metastatic melanoma

Gene mutation testing

If the melanoma has spread (stage 3 or 4), you may have tests for a particular gene change (mutation). These gene mutations are due to changes in cancer cells – they occur during a person's lifetime, and are not the same thing as genes passed through families.

About 30–40% of people with melanoma have the BRAF mutation gene, which makes the cancer cells grow and divide faster. About 15% have a mutation in the NRAS gene, which controls how cells divide. C-KIT is a rare mutation affecting less than 4% of people with melanoma.

Genetic tests can be done on the tumour tissue sample removed during surgery. The test results will help doctors work out whether particular drug therapies may be useful (see pages 33–36).

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for anyone to predict the exact course of the disease. Instead, your doctor can discuss any concerns you may have.

Melanoma can be treated most effectively in its early stages when it is still confined to the top layer of the skin (epidermis). The more deeply a melanoma grows into the lower layer of the skin (dermis), the greater the risk that it could spread to nearby lymph nodes or other organs.

In recent years, new drug treatments such as immunotherapy and targeted therapy (see pages 33–36) have improved the prognosis for people with melanoma that has spread from the primary site (advanced or metastatic melanoma) or is at very high risk of spreading.

Key points about diagnosing melanoma

Main tests

Tests to diagnose melanoma include:

- physical examination of the suspicious spot or mole and any other moles on your body with dermoscopy, which involves a handheld magnifying instrument called a dermatoscope.
- photos of the body (known as total body photography) to check for changes over time
- removal of a spot on your skin for examination by a pathologist. This is called an excision biopsy. The biopsy will provide information about the thickness of the melanoma (Breslow thickness) and how deeply into the skin the cancer cells have grown.

Other tests

Your doctor will feel the nearby lymph nodes to work out if the melanoma has spread to other parts of the body. To check the lymph nodes for cancer cells, you may have a:

- needle biopsy
- sentinel lymph node biopsy.

Gene mutation testing

The tissue sample may be tested for gene mutations in the cancer cells.

Staging and prognosis

The stage shows how far the melanoma has spread:

- early or localised melanoma is stages 0–2
- regional melanoma is stage 3
- advanced or metastatic melanoma is stage 4.

For stage 3 or 4, gene mutation testing of tissue samples is highly recommended.

Your doctor may talk to you about the prognosis, which is the expected outcome for your type and stage of melanoma.



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started.

Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 14) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 51 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

► See our *Cancer Care and Your Rights* booklet.

Should I join a clinical trial?

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and

led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

► See our *Understanding Clinical Trials and Research* booklet.



Treatment for early melanoma

Surgery is the most common treatment for melanoma that is found early (stages 0-2 or localised melanoma). If the risk of the melanoma spreading is high or it has spread to nearby lymph nodes or tissues (stage 3 or regional melanoma), treatment may also include removing lymph nodes and additional (adjuvant) treatments.

Surgery (wide local excision)

Most people diagnosed with melanoma have more surgery after the spot has been removed with an excision biopsy (see pages 16-17). The second surgery removes more normal-looking skin from around the melanoma (wider margin). This is known as a wide local excision.

Removing more skin around the melanoma reduces the risk of it coming back (recurring) at that site. The width of the margin is usually between 5 mm and 10 mm, depending on the type, thickness and location of the melanoma. For thicker tumours, a wider margin of up to 20 mm may be advised.

A wide local excision is often performed as a day procedure. This means you can go home soon after the surgery if there are no complications. If the melanoma is thicker than 1 mm or is considered high risk for spread to the lymph nodes, the doctor will discuss the risks and benefits of a sentinel lymph node biopsy (see page 18). If you need a sentinel node biopsy, it is done at the same time as the wide local excision.

▶ See our *Understanding Surgery* booklet.

Checking for a clear margin

After a wide local excision, the tissue removed from around the melanoma will be sent to a laboratory. The pathologist will check that the required margin has been taken; this is called a clear margin. If the margins need to be wider, you may need to have further surgery to remove more tissue.

Repairing the wound

The wound is often closed with stitches. You will have a scar but this will usually become less noticeable with time. If a large area of skin is removed, the surgeon may repair the wound using skin from another part of your body. This can be done in two ways:

Skin flap – Nearby skin and fatty tissue are lifted and moved over the wound from the edges and stitched.

Skin graft – A layer of skin is taken from another part of your body (most often the thigh or neck) and placed over the area where the melanoma was removed. The skin grows back quickly, usually over a few weeks.

Whether the surgeon does a skin flap or graft will depend on a number of factors, including:

- where the melanoma is
- how much tissue has been removed
- your general health.

In either case, the wound will be covered with a dressing. After several days, the doctor will check to see if the wound is healing properly. If you had a skin graft, you will also have a dressing on any area that had skin removed for the graft.

What to expect after surgery

Most people recover quickly after a wide local excision to remove a melanoma, but you will need to keep the wound clean.

Pain relief



The area around the wide local excision may feel tight and tender for a few days. Your doctor will prescribe pain medicine if necessary.

Wound care



Your medical team will tell you how to keep the wound clean to prevent it from becoming infected.

Occasionally, the original skin flap or graft doesn't heal. In this case, you will need to have another procedure to create a new flap or graft.

Skin changes



If you have a skin graft, the area that had skin removed may look red and raw immediately after the operation. Over a few weeks, this area will heal, and the redness will fade.

Recovery time



The time it takes to recover will vary depending on the thickness of the melanoma and the extent of the surgery required. Most people recover in 1–2 weeks. Ask your doctor how long to wait before returning to your usual exercise and activities.

When to seek advice



Talk to your doctor if you have any unexpected bleeding, bruising, infection, scarring or numbness after surgery.

Removing lymph nodes

Many people with melanoma will not need to have any lymph nodes removed. Lymph nodes may need to be removed for several reasons:

Sentinel lymph node – If the melanoma is thicker than 1 mm or has high-risk features, you may have a sentinel lymph node biopsy (see page 18) at the same time as the wide local excision.

Further scans and treatment – If a sentinel node biopsy shows melanoma is found in the removed node, you will need to have regular imaging scans to check that the melanoma has not come back or spread. You may also be offered drug therapy (see pages 33–36) to reduce the risk of the melanoma returning.

Lymph node dissection – If your lymph nodes feel or look swollen, and a fine needle biopsy (see pages 17–18) confirms that a lymph node contains melanoma – you may need to have all the lymph nodes in that area removed under a general anaesthetic. This operation is called a lymph node dissection or lymphadenectomy, and may mean a longer stay in hospital. Your doctor may also suggest you have targeted therapy or immunotherapy before surgery (neoadjuvant treatment). This treatment is best done at a melanoma unit.

Side effects of lymph node removal

Having your lymph nodes removed can cause side effects. These are likely to be milder if you only have a sentinel node biopsy.

Wound pain – Most people will have some pain after the operation, which usually improves as the wound heals. For some people, the pain may be ongoing, especially if lymph nodes were removed from the neck. Talk to your medical team about how to manage any pain.

Neck/shoulder/hip stiffness and pain – These are the most common problems if lymph nodes in your neck, armpit or groin were removed. You may find that you cannot move the affected area as freely as you could before the surgery. It may help to do gentle exercises or ask your GP or cancer care team to refer you to a physiotherapist.

Seroma/lymphocele – This is a collection of fluid in the area where the lymph nodes have been removed. It is a common side effect and appears straight after surgery. It usually gets better after a few weeks, but sometimes your surgeon may drain the fluid with a needle.

Lymphoedema – This is a swelling of the neck, arm or leg that may appear after the lymph nodes are removed. Lymphoedema happens when lymph fluid builds up in the affected part of the body because the treatment has impacted the lymphatic system.

Managing lymphoedema

Your risk of developing lymphoedema depends on the extent of the surgery and whether you've had radiation therapy (see pages 36–37) .

Lymphoedema can develop a few weeks, or even several years, after treatment. Although this condition may be permanent, it can usually be managed, especially if treated at the earliest sign of swelling or heaviness.

A lymphoedema practitioner can help you manage lymphoedema. To find a trained practitioner, visit lymphoedema.org.au or ask your doctor for a referral. You may need to wear a professionally fitted compression garment. Massage and regular exercise, such as swimming, cycling or yoga, can help the lymph fluid flow. Keeping the skin healthy can help reduce the risk of infection.

► See our *Understanding Lymphoedema* fact sheet.

Further treatment after surgery

If there's a risk that the melanoma could come back (recur) after surgery, other treatments are sometimes used to reduce the risk. These are known as adjuvant (or additional) treatments. They may be used alone or together.

Some treatments use drugs that enter the bloodstream and travel throughout the body. This is known as systemic treatment.

The main systemic treatments for melanoma are:

- **immunotherapy** – drugs that use the body's own immune system to recognise and fight some types of cancer cells
- **targeted therapy** – drugs that attack specific features within cancer cells known as molecular targets to stop the cancer growing and spreading.

Chemotherapy is another form of systemic drug treatment. It is used to treat many cancers, but it is rarely used for melanoma because immunotherapy and targeted therapy drugs usually work better.

In some cases, people with melanoma may be offered radiation therapy (also known as radiotherapy). This is the use of targeted radiation to damage or kill cancer cells in a particular area of the body. Radiation therapy may be used if the melanoma has spread to the brain, but the increasing use of immunotherapy and targeted therapy is making this less likely.

For further information about immunotherapy, targeted therapy and radiation therapy, see the *Treatment for advanced melanoma* chapter on pages 33–39. Your doctor may also suggest you join a clinical trial (see page 25).

Key points about treating early melanoma

What it is

Melanoma is a type of skin cancer. Early or localised melanoma has not spread outside the primary site. Regional melanoma has spread to nearby lymph nodes, skin or tissue.

The main treatment

The main treatment is surgery to remove the suspicious area. Most people will have further surgery to remove more normal-looking tissue from around the melanoma (wider margin).

Removing lymph nodes

Many people with early melanoma will not need to have any lymph nodes removed. If melanoma has high-risk features or has spread to the lymph nodes, you may have one of the following procedures:

- sentinel lymph node biopsy – removes the lymph nodes that a melanoma may have spread to first to detect the disease as early as possible
 - lymph node dissection or lymphadenectomy – removes lymph nodes if a fine needle biopsy shows the melanoma has spread to them and caused lumps.
-

Further treatments

You may also have other treatments to reduce the risk of the melanoma coming back. This may be before (neoadjuvant) or after (adjuvant) surgery, and may include:

- immunotherapy – drugs that use the body's own immune system to fight melanoma
 - targeted therapy – drugs that attack specific features of cancer cells to stop the melanoma growing and spreading
 - radiation therapy – use of targeted radiation to damage melanoma cells in a specific area.
-

Treatment for advanced melanoma

When melanoma has spread to distant lymph nodes, internal organs or bones (stage 4), it is known as advanced or metastatic melanoma. Treatment may include immunotherapy, targeted therapy, radiation therapy and surgery. Palliative treatment may also be offered to help manage symptoms and improve quality of life (see page 38). Since more effective treatments are now available, chemotherapy is rarely used to treat melanoma.

You will be offered a treatment plan based on factors such as the features of the melanoma, where it has spread and any symptoms you have. New developments are occurring all the time, and you may be able to get new treatments through clinical trials (see page 25).

Immunotherapy

Immunotherapy drugs called checkpoint inhibitors use the body's own immune system to fight cancer. Some people who use checkpoint inhibitors have had very encouraging results, but they do not work for everyone with advanced melanoma.

Checkpoint inhibitors used for advanced melanoma include ipilimumab, nivolumab and pembrolizumab. Sometimes more than one drug is used, and different combinations work for different people.

You will usually have immunotherapy as an outpatient, which means you visit the treatment centre for the day. In most cases, the immunotherapy drugs are given into a vein (intravenously). You may have treatment every

2–6 weeks in a repeating cycle for up to 2 years, but this depends on how the melanoma responds to the drugs and any side effects that you have.

Other immunotherapy treatments are being tested in clinical trials. Talk to your doctor about whether immunotherapy is an option for you.

Side effects of immunotherapy

The side effects of immunotherapy drugs will vary depending on which drugs you are given and can be unpredictable. Immunotherapy can cause inflammation in any of the organs in the body, which can lead to side effects such as tiredness, joint pain, diarrhoea, and an itchy rash or other skin problems. The inflammation can lead to more serious side effects in some people, and in rare cases this can be life threatening, but these side effects will be monitored closely and managed quickly.

You may have side effects within days of starting immunotherapy, but more often they occur many weeks or months later. It is important to discuss any side effects with your treatment team as soon as they appear so they can be managed appropriately. When side effects are treated early, they are likely to be less severe and last for a shorter time.

Delaying or stopping treatment for a side effect does not mean immunotherapy will stop working. There are many patients who stopped treatment after only one or a few treatments and whose melanoma remains controlled years later without further treatment.

▶ See our *Understanding Immunotherapy* fact sheet.



It is important to let your doctor know immediately of any side effects from immunotherapy or targeted therapy treatment. If left untreated, some side effects can become very serious and even life threatening.



Steve's story

My wife convinced me to have a spot on my back checked. The skin specialist said it needed to be cut out and biopsy results came back for a melanoma.

I was referred to the Melanoma Institute in Sydney where I had a series of dye injections, CT and MRI scans and ultrasound. These showed the melanoma had spread to at least 2 lymph nodes. The next day, I had surgery to remove the melanoma and a number of lymph nodes.

Because the pathology results showed that I still had a small positive margin, the surgeon referred me to a medical oncologist. She put me on a clinical trial for the immunotherapy drug nivolumab. I had to have an infusion every 2 weeks for 12 months. I was able to have the nivolumab infusions and follow-up scans every 3 months in my regional town.

After 6 months of immunotherapy and feeling happy with the results of the first scans, the results of

my second MRI and CT scans hit me like a high-speed train. They showed tumours in my brain, liver, kidney and spleen. The oncologist suggested I continue with nivolumab and also try ipilimumab every 3 weeks for 3 months. I also saw a radiation oncologist, who suggested stereotactic radiosurgery. The medical oncologist explained all the side effects and warned me that I would probably experience a few.

The immunotherapy and the stereotactic radiosurgery left me with several side effects. These included rashes, mouth ulcers, headaches and loss of appetite, and more severe ones such as joint pain and a type of arthritis called spondyloarthritis. My doctor has been able to fix most of my side effects.

A year later, the MRI and CT scans are all clear. I think I'm almost back to my old self, but I get anxious the week of the scans until I get the results. I wouldn't have made it this far without the medical staff and the support of my wife.

Targeted therapy

New types of drugs known as targeted therapy attack specific features of cancer cells to stop the cancer growing and spreading. Your doctor will check if the melanoma has a specific mutation (see page 22) before offering you a targeted therapy drug.

If a person has a BRAF mutation, they will get both a BRAF inhibitor and a MEK inhibitor. Three commonly used combinations include dabrafenib and trametinib; vemurafenib and cobimetinib; and encorafenib and binimetinib. Drugs for NRAS and C-KIT mutations may be available through clinical trials – talk to your doctor about whether one of these trials is right for you.

Targeted therapy drugs are generally taken as tablets (orally) once or twice a day, often for many months or even years. Cancer cells can become resistant to targeted therapy drugs over time. If this happens, your doctor may suggest trying another targeted therapy drug or another type of treatment.

Side effects of targeted therapy

The side effects of targeted therapy will vary depending on which drugs you are given. Common side effects include fever, tiredness, joint pain, rash and other skin problems, loss of appetite, nausea and diarrhoea.

Ask your treatment team how you can deal with any side effects.

► See our *Understanding Targeted Therapy* fact sheet.

Radiation therapy

Also known as radiotherapy, radiation therapy is the use of targeted radiation, such as x-ray beams, to kill or damage cancer cells. Radiation therapy may be offered on its own or with other treatments. In rare cases,

it is used after surgery to prevent melanoma coming back. It can also help relieve pain and other symptoms caused by melanoma that has spread to the brain or bone (palliative treatment, see next page).

Before starting treatment, you will have a CT or MRI scan at a planning appointment. The technician may make some small permanent or temporary marks on your skin so that the same area is targeted during each treatment session.

Treatment sessions are usually given daily over 1–4 weeks. The number of sessions will depend on the size and location of the tumour, and your general health. For the treatment, you will lie on a table under a machine that aims radiation at the affected part of your body. Each session takes about 20–30 minutes and is painless.

In some cases, you may be offered a specialised type of radiation therapy that delivers highly precise, tightly-focused beams of high-dose radiation onto the tumour from many different angles. This is called stereotactic radiosurgery (SRS) when used on the brain, and stereotactic body radiation therapy (SBRT) when used on other parts of the body. SBRT often involves 3–5 treatment sessions over 1–2 weeks.

Side effects of radiation therapy

The side effects that you experience will depend on the part of the body that receives radiation therapy and how long you have treatment. Many people will have temporary side effects, which may build up over time. Common side effects during or immediately after radiation therapy include tiredness, and the skin in the treatment area becoming red and sore. Ask your treatment team for advice about dealing with any side effects.

► See our *Understanding Radiation Therapy* booklet.

Surgery

In some cases, surgery may be recommended for people with advanced melanoma. It is used to remove melanoma from the skin (see pages 26–28), lymph nodes (see pages 29–30), or other organs such as the lung or brain. Your suitability for surgery will be discussed at a multidisciplinary team meeting (see page 14).

Talk to your treatment team about what the surgery involves and what recovery will be like. Side effects will depend on the type of surgery, but often include pain and risk of infection (see pages 28–30).

▶ See our *Understanding Surgery* booklet.

Palliative treatment

In some cases of advanced melanoma, the medical team may talk to you about palliative treatment. Palliative treatment aims to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It can be used at any stage of advanced cancer and does not mean giving up hope. Some people have palliative treatment as well as active treatment of the melanoma.

When used as palliative treatment, radiation therapy and medicines can help manage symptoms caused by advanced melanoma, such as pain, nausea and shortness of breath.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, cultural, social and spiritual needs. The team also supports families and carers.

▶ See our *Living with Advanced Cancer* and *Understanding Palliative Care* booklets.

Key points about treating advanced melanoma

What it is

If melanoma has spread to other parts of your body (distant areas of skin, distant lymph nodes or internal organs or bones), it is called advanced or metastatic melanoma.

Treatments

Treatment options for advanced melanoma depend on where the cancer has spread to, various test results and whether the cancer has a particular gene mutation. Treatments may include:

- immunotherapy – drugs that use the body's own immune system to fight melanoma
 - targeted therapy – drugs that attack specific features of melanoma cells
 - radiation therapy – uses targeted radiation to damage melanoma cells
 - surgery – removes melanoma from the skin, lymph nodes or organs
 - palliative treatment – seeks to improve quality of life without aiming to cure the cancer.
-

Side effects

- Immunotherapy drugs can cause inflammation of any organ in the body. Common side effects include joint pain, diarrhoea and skin rash.
 - Targeted therapy can cause fever, tiredness, joint pain, skin rash and other side effects.
 - Radiation therapy may cause tiredness and skin reactions.
 - Surgery can cause pain, risk of infection and other side effects.
-

Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

▶ See our *Nutrition for People Living with Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

▶ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

▶ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested, may prevent successful treatment of the cancer and can be harmful. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▶ See our *Cancer and Your Finances* and *Cancer, Work and You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. The experience of cancer may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

▶ See our *Emotions and Cancer* booklet.

Sexuality – Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

▶ See our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

▶ See our *Fertility and Cancer* booklet.

How to protect your skin from the sun

Most melanomas are caused by exposure to the sun's UV radiation. After a diagnosis of melanoma, it is especially important to check your skin regularly

Slip on clothing



Wear clothing that covers your shoulders, neck, arms, legs and body. Choose closely woven fabric or fabric with a high ultraviolet protection factor (UPF) rating, and darker fabrics where possible.

Slap on a hat



Wear a hat that shades your face, neck and ears. This includes legionnaire, broad-brimmed and bucket hats. Check to make sure the hat meets the Australian Standard. Choose fabric with a close weave that doesn't let the light through. Baseball caps and sun visors do not offer enough protection.

Slop on sunscreen



Use an SPF 30 or higher broad-spectrum, water-resistant sunscreen. Apply 20 minutes before going outdoors and reapply every 2 hours, or after swimming, sweating or any activity that causes you to rub it off. For an adult, the recommended amount is 1 teaspoon for each arm, each leg, front of body, back of body, and the face, neck and ears – a total of 7 teaspoons of sunscreen for one full body application.

Slide on sunglasses



Protect your eyes with sunglasses that meet the Australian Standard. Wraparound styles are best. Sunglasses should be worn all year round to protect both the eyes and the delicate skin around the eyes.

(see page 10) and follow SunSmart behaviour. When UV levels are 3 or above, use all or as many of the following measures as possible to protect your skin.

Seek shade



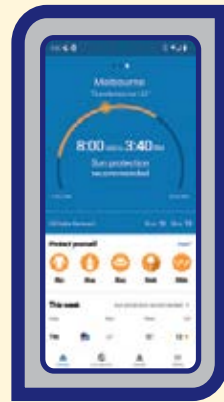
Use shade from trees, umbrellas, buildings or any type of canopy. UV radiation is reflective and bounces off surfaces, such as concrete, water, sand and snow, so shade should never be the only form of sun protection used. If you can see the sky through the shade, even if the direct sun is blocked, the shade will not completely protect you from UV radiation.

Avoid solariums



Do not use solariums. Also known as tanning beds or sun lamps, solariums give off artificial UV radiation and are banned for commercial use in Australia.

Check daily sun protection times



Each day, use the free SunSmart app to check the recommended sun protection times in your local area. For more information, visit sunsmart.com.au.

You can also find sun protection times at the Bureau of Meteorology (bom.gov.au or the BOM Weather app) or in the weather section of daily newspapers.

Understanding sun protection

After a melanoma diagnosis, you need to take special care to protect your skin from the sun's UV radiation. This will reduce your risk of further melanomas.

The UV Index shows the intensity of the sun's UV radiation. It can help you work out when to use sun protection. An index of 3 or above means that UV levels are high enough to damage unprotected skin, and you need to use more than one type of sun protection. The recommended daily sun protection times (see previous page) are the times of day the UV levels are expected to be 3 or higher. These will vary according to where you live and the time of year.

Sun exposure and vitamin D

UV radiation from the sun causes skin cancer, but it is also the best source of vitamin D. People need vitamin D to develop and maintain strong, healthy bones. The body can absorb only a set amount of vitamin D at a time. Most people get enough vitamin D through incidental exposure to the sun, while using sun protection. When the UV Index is 3 or above, this may mean spending just a few minutes outdoors on most days of the week, depending on where in Australia you live and the time of year.

After a diagnosis of melanoma, talk to your doctor about the best ways to get enough vitamin D while reducing your risk of getting more melanomas. Your doctor may advise you to limit your sun exposure as much as possible when the UV Index is 3 or above. In some cases, this may mean you don't get enough sun exposure to maintain your vitamin D levels. Your doctor may advise you to take a supplement.

Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after melanoma treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the melanoma is coming back.

Some people say that they feel pressure to return to "normal life". It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other people who have had melanoma, and provide you with information about the emotional and practical aspects of living well after cancer.

► See our *Living Well After Cancer* booklet.

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.

Follow-up appointments

After you have had one melanoma, you have about 5 times the risk of developing a new melanoma compared with the average person of the same age. It is important to be familiar with your skin, examine it for changes (see page 9) and go to your follow-up appointments.

Your doctor can give you more details of how often you need follow-up appointments – more frequent visits are recommended for people with advanced melanoma. At these appointments, your doctor will examine the area that was treated and your lymph nodes to check that the melanoma hasn't come back or spread. Your doctor will also check the rest of your skin for any new melanomas. Sometimes you will need to have regular CT scans or PET scans before follow-up appointments.

You may feel anxious before a follow-up appointment or test. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

What if the melanoma returns?

For most people, early melanoma will not come back (recur) after treatment. The risk of the melanoma returning is higher for people with regional melanoma. Recurrence can occur at the site where the melanoma was removed (locally); in the lymph nodes; or further away in other body sites, such as the lung, liver or brain.

If the cancer returns, your doctor will discuss the treatment options with you. These will depend on where the cancer has recurred, as well as the number of sites, its extent and your general health. You may be offered immunotherapy, targeted therapy or the option to join a clinical trial.

Caring for someone with cancer

You may be reading this booklet because you are caring for someone with melanoma. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with the practical and emotional aspects of your caring role.

Support services – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers Australia – Carers Australia provides information and advocacy for carers. Visit carersaustralia.com.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

▶ See our *Caring for Someone with Cancer* booklet.

Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost. To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, get in touch with Cancer Council 13 11 20, or call Melanoma Patients Australia's National Melanoma Support Line on 1300 884 450.



Surgery for melanoma often leaves a scar, but this will usually fade with time. If you're worried about how the scar looks, especially if it's on your face, you can use cosmetics, hairstyles and clothing to help cover the scar. Look Good Feel Better is a national program that helps people manage the appearance-related effects of cancer treatment. For information about workshops in your area, call 1800 650 960 or visit lgfb.org.au.

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

Legal and financial support



If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council 13 11 20 to ask if you are eligible.

Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

Peer support services



You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit cancercouncil.com.au/OC.

Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

Cancer Council Australia	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Guides to Best Cancer Care	cancer.org.au/cancercareguides
Cancer Australia	canceraustralia.gov.au
Carer Gateway	carergateway.gov.au
Healthdirect Australia	healthdirect.gov.au
Melanoma and Skin Cancer Trials	masc.org.au
Melanoma Institute Australia	melanoma.org.au
Melanoma Patients Australia (including the National Melanoma Support Line)	melanomapatients.org.au
Melanoma WA	melanomawa.org.au
Services Australia (including Medicare and Centrelink)	servicesaustralia.gov.au
SunSmart	sunsmart.com.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk
Melanoma Research Foundation (US)	melanoma.org
Melanoma UK	melanomauk.org.uk
Skin Cancer Foundation (US)	skincancer.org

Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of melanoma do I have? How thick is it?
 - Has the melanoma spread? How fast is it growing?
 - Did the biopsy remove all of the melanoma?
 - Are the latest tests and treatments for melanoma available in this hospital?
 - Can you explain the results of the tests to me?
 - Are there clinical guidelines for this type of melanoma?
-

Treatment

- What treatment do you recommend? What is the aim of the treatment?
 - How long will treatment take? Will I have to stay in hospital?
 - How much will treatment cost? Can the cost be reduced if I can't afford it?
 - How will I know if the treatment is working?
 - Are there any clinical trials or research studies I could join?
-

Side effects

- What are the risks and possible side effects of each treatment? How can these be managed?
 - Will I have a lot of pain? If I do, what will be done about this?
 - Will there be any scarring after the melanoma is removed?
 - What are the chances I will get lymphoedema after treatment?
-

After treatment

- How often will I need to get my skin checked after treatment? Who should I go to for my skin checks?
 - How can I protect myself from the sun and get enough vitamin D?
 - If the melanoma returns, how will I know? What treatments could I have?
 - Are there any local support groups for people with melanoma?
-

Glossary

ABCD guidelines

A set of signs used to help identify melanoma. The letters stand for: A=Asymmetry, B=Border, C=Colour and D=Diameter.

acral lentiginous melanoma

A rare type of melanoma of the skin that occurs on the palms of the hands, soles of the feet or under the nails.

adjuvant treatment

A treatment given after the main treatment to lower the risk that the cancer will come back (recur).

advanced melanoma

Melanoma that has spread to other parts of the body. Also known as secondary or metastatic cancer.

anaesthetic

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

basal cell carcinoma (BCC)

A type of skin cancer that begins in the basal cells in the top layer of the skin (epidermis). See also non-melanoma skin cancer.

basal cell layer

The lowest layer of the top layer of the skin (epidermis).

benign

Not cancerous or malignant.

biopsy

The removal of a sample of tissue from the skin for examination under a microscope.

BRAF gene mutation

A non-inherited gene change that can tell cancer cells to multiply.

Breslow thickness

A description of a melanoma's thickness in millimetres from the top layer of the skin to its deepest point in the skin.

cells

The basic building blocks of the body. A human is made of billions of cells that perform different functions.

checkpoint inhibitors

Drugs that work by helping the immune system to attack the cancer.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

C-KIT mutation

A non-inherited gene change that can tell cancer cells to multiply.

Clark level

A number (1–5) that describes how many layers of skin a melanoma has gone through.

clinical trial

A research study that tests new approaches to prevention, screening, diagnosis or treatment, to see if they are better than current approaches.

CT scan

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

cutaneous melanoma

Melanoma that starts in the skin.

dermis

The lower layer of the two main layers that make up the skin.

dermoscopy

Procedure to examine closely the surface of the skin using a dermatoscope.

desmoplastic melanoma

A rare type of melanoma of the skin. May be mistaken for a scar.

epidermis

The top, outer layer of the two main layers that make up the skin.

excision biopsy

A type of biopsy where an area of abnormal tissue is surgically removed (excised).

fine needle biopsy

The removal of a tissue sample with a fine needle. Also called a fine needle aspiration.

genes

The microscopic units that determine how the body's cells grow and behave.

immunotherapy

Drugs that use the body's own immune system to fight cancer.

intravenous (IV)

Injected into a vein.

keratinocyte cancer

See non-melanoma skin cancer.

lentigo maligna melanoma

A type of melanoma of the skin that starts as a large, coloured spot (lentigo maligna).

lesion

An area of abnormal tissue.

localised melanoma

A melanoma that has not spread from its original site to lymph nodes or other organs in the body.

lymphatic system

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells.

lymph node dissection

Removal of the lymph nodes from a part of the body. Also called lymphadenectomy.

lymph nodes

Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. Also called lymph glands.

lymphocele

See seroma.

lymphoedema

Swelling caused by a build-up of lymph fluid. Can develop in the neck, arm or leg.

lymphovascular invasion

Shows if cancer cells have spread to the blood vessels or lymphatic system.

lymph vessels

Thin tubes that carry the clear fluid known as lymph all over the body.

malignant

Cancerous. Malignant cells can spread (metastasise) and eventually cause death if they cannot be treated.

margin

The edge of tissue removed during surgery. Clear or negative margin means no cancer cells were found on the edge of the removed tissue. Positive margin means cancer cells were found on the edge of the tissue.

melanin

Dark pigment produced in melanocytes that gives skin its colour.

melanocyte

One of the three types of cells that make up the top layer of the skin (epidermis). Melanocytes produce melanin.

melanoma

Cancer of the melanocytes. Usually appears on the skin but may affect the eye, mucous membrane or the nervous system. See also ocular melanoma, mucosal melanoma.

melanoma in situ

An early melanoma that is confined to the top layer of the skin (epidermis).

metastasis (plural: metastases)

A cancer that has spread from a primary cancer in another part of the body. Also known as secondary cancer.

mitotic rate

A measure of how quickly the melanoma cells divide.

mole

See naevus.

mucosal melanoma

A rare type of melanoma that starts in the tissues of the mouth, anus, urethra, vagina or nasal passages.

naevus (plural: naevi)

A small pink, brown, black or blue spot on the skin that arises from skin cells called melanocytes. Also called a mole.

nodular melanoma

A type of melanoma of the skin. It often grows fast.

non-melanoma skin cancer

Skin cancer that doesn't develop from melanocyte cells, e.g. basal cell cancer (BCC) or squamous cell cancer (SCC). Also known as keratinocyte cancer.

NRAS gene mutation

A non-inherited gene change that can cause cells to grow and divide uncontrollably.

ocular melanoma

A rare type of melanoma that starts in the eye.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms.

PET-CT scan

Positron emission tomography scan

combined with CT scan. In a PET scan, you are injected with a small amount of radioactive glucose solution. This makes cancerous areas show up brighter on the scan.

primary cancer

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

primary site

The part of the body where the cancer first developed.

prognosis

The expected outcome of a particular person's disease.

radiation therapy (radiotherapy)

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams.

recurrence

The return of a disease after a period of improvement (remission).

regional melanoma

Melanoma that has spread from its original site to nearby lymph nodes or tissues.

regression

An area within a melanoma where melanoma cells have been destroyed and replaced by inflammation or scar tissue.

sentinel lymph node biopsy

A surgical procedure used to determine whether a melanoma has spread from the primary site to the lymphatic system.

sentinel node

The first lymph node that melanoma is likely to spread to from the original site.

seroma

A collection of fluid under a wound after an operation. Also called a lymphocele.

skin flap

A procedure where a melanoma has been removed and nearby skin or fatty tissue is pulled over the wound and stitched.

skin graft

A procedure where a melanoma has been removed and a layer of skin is removed from one part of the body and fixed over the wound that is left.

squamous cell carcinoma (SCC)

A type of skin cancer that begins in the squamous cells in the top layer of the skin. See also non-melanoma skin cancer.

stage

The extent of a cancer and whether the disease has spread from the original site to other parts of the body.

superficial spreading melanoma

The most common melanoma of the skin. It often grows slowly.

systemic treatment

Treatment that affects the whole body.

targeted therapy

Drugs that attack specific cancer cell features to stop the cancer growing and spreading.

tissue

A collection of cells of similar type that make up an organ or structure in the body.

total body photography

Photos of the body to monitor the skin.

trunk

The part of the body between the shoulders and hips.

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

ulceration

The breakdown or loss of the outer layer of skin.

ultraviolet (UV) radiation

The part of sunlight that causes tanning, sunburn and skin damage. It is also produced by solariums (also called tanning beds or sun lamps). UV radiation cannot be seen or felt.

UV index

An international standard measure of the intensity of the sun's ultraviolet radiation.

wide local excision

A surgical procedure to remove a melanoma and some of the healthy tissue around it.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
 - cancervic.org.au/glossary
-

References

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2. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia 2022*, AIHW, Canberra, viewed 4 October 2022, available from aihw.gov.au/reports/cancer/cancer-data-in-australia.
3. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2021*, AIHW, Canberra, 2021.



How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council

13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our experienced health professionals are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs

*Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).*

For information & support
on cancer-related issues,
call **Cancer Council 13 11 20**

Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council Queensland
cancerqld.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council NSW
cancercouncil.com.au

Cancer Council SA
cancersa.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council NT
cancer.org.au/nt

Cancer Council Tasmania
cancer.org.au/tas

Cancer Council Australia
cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*

