



A guide to **Understanding Melanoma**

a starting point for people in
their journey with melanoma

Foreword

**“Patient support is the foundation stone of MPA,
upon which everything else is built.”**

Melanoma Patients Australia prides itself on offering dedicated and responsive support to melanoma patients, their families and friends.

Melanoma Patients Australia has developed this Patient Guide to provide a starting point for people in their journey with melanoma. It is important to MPA that patients know they have access to information and a network of support.

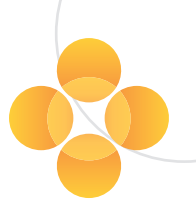
This guide offers introductory information to melanoma patients as well as their carers, family and friends. Throughout this booklet you will find references to external resources and organisations that can provide you with more in depth information and specific advice regarding your personal situation.

Most importantly, after reading this Patient Guide if you require further up to date information we recommend that you start with our website, www.melanomapatients.org.au, where you will find recent research findings, links to support and medical organisations as well as all of our patient services.

Wherever you are on your melanoma journey, Melanoma Patients Australia is here to support you. Being diagnosed with melanoma can be an isolating, confusing and frightening experience and hopefully this booklet can clarify some of the questions you may have.

John Seccombe

Chairman
Melanoma Patients Australia



What is Melanoma Patients Australia?

Vision

Creating a world where no one affected by melanoma walks alone.

Purpose

To support, connect and advocate for Australians affected by melanoma and work towards its prevention.

Melanoma Patients Australia (“MPA”) was founded by two young melanoma patients, Brent Grace (now deceased) and Daniel Belcher, and was officially launched on 6 July 2006 by the then Governor of Queensland, The Honourable Dame Quentin Bryce AD CVO.

Melanoma Patients Australia is the only patient driven non-profit organisation that offers a national network of support and information to patients, their families, carers, and friends, about melanoma prevention, diagnosis, management and treatment. MPA continues to grow in strength and numbers and is now one of the largest melanoma patient advocacy groups in Australia.

MPA Patient Programs and Services - How we can help you?

Melanoma Patients Australia continuously strives to provide current, relevant and patient focussed programs and services accessible to all melanoma patients across Australia. We also offer guidance, support and assistance to the family, friends and carers of melanoma patients as we understand that a diagnosis with melanoma may have a significant impact upon their lives too. Examples of some the initiatives undertaken by MPA include:

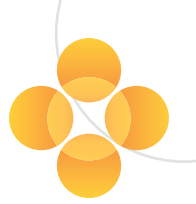
- > Offering a community of friendship and peer to peer support to melanoma patients,

their families, carers and friends. We do this through face to face and telephone support groups as well as on-line groups and resources (website www.melanomapatients.org.au) and social media.

- > Providing high quality melanoma specific information and resources.
- > Providing information, and support to assist people affected by melanoma including emotional and practical support through the National Melanoma Support Line 1300 884 450
- > Advocating on behalf of patients to all levels of government, as well as relevant service organisations, researchers and corporations.
- > Representing an independent melanoma patient voice on national panels and advisory boards.
- > Supporting research and clinical trials seeking to offer the best options for melanoma patients.
- > Raising awareness of sun safety in the community.

It is vital that all melanoma patients are given the best available support and care and it is for this reason we rely on the support of financial sponsors, donors and contributors to ensure our continued operation. Our members play a pivotal role in hosting fundraising events with proceeds going to MPA to ensure the important role of MPA continues.





Support and Information Services

Melanoma Patients Australia provides support across Australia to melanoma patients, their families, friends and carers.

MPA offers a range of support services for you to access - the choice is yours as it is important that you do what you are most comfortable with.

- > **Telephone support:** Information, and support to assist people affected by melanoma including emotional and practical support is available **1300 884 450** (cost of a local call anywhere in Australia). Also regular Telephone Support Groups for those with metastatic melanoma.
- > **Support Group Meetings:** Meet other members, listen to speaker presentations from various organisations, attend social events.
- > **Online Support:** Is available for you to reach out for friendship, information and guidance.
- > **Workshops and Forums:** Melanoma Patients Australia regularly hosts information sessions to assist in gaining a better understanding of melanoma and its management.
- > **Provide information:** the MPA guide and website provide regularly updated information to ensure patients and their families are well informed about all aspects of melanoma, including treatments and support options.

“This support group has given me the opportunity to meet and support others that have had the same cancer, some even worse than me”

Regan, MPA member

“Being diagnosed with melanoma has put new meaning into my life. I have always known that you should live your life to the full every moment of every day – but there is a difference between ‘knowing’ something like that and ‘understanding’ what it really means.”

George, MPA member

Melanoma: A Medical Overview

Anatomy of the Skin

In order to understand what melanoma is, it is first important to understand the structure of your skin.

The skin constitutes 16% of the human body weight and is comprised of three main layers; the epidermis, dermis and fat. The dermis and adjacent fatty tissue layers are not visible to the naked eye. Skin is rich in cell types that have the potential to grow cancer if exposed to repeated ultraviolet trauma, such as excessive sun exposure.

The layers of the skin have been split into levels for the purposes of assessing the depth a skin cancer may have penetrated. Level I is the epidermis, the most superficial layer. Level II, III and IV are within the next layer called the dermis. The Dermis is composed of two layers - the upper layer (Papillary) and the lower layer (the Reticular). Level V is the Hypodermis which is the subcutaneous fat layer under the skin.

What is Melanoma?

The melanocyte is a cell in the epidermis. Melanoma is an uncontrolled abnormal growth of the melanocyte cells.

Primary Melanoma

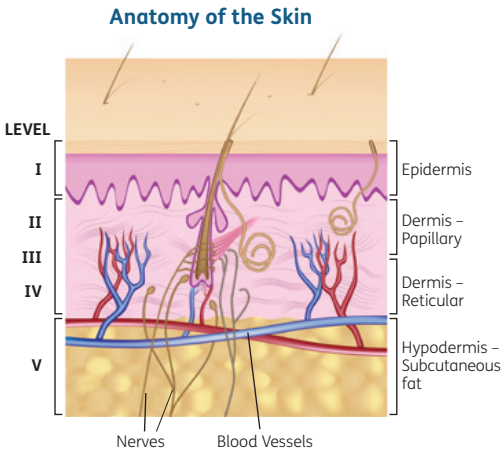
Primary melanoma refers to the first instance when the melanoma occurs, typically in the skin. The primary melanoma most commonly starts in the epidermis but can be present in some patients in the eyes, mouth, ears and other parts of the body containing melanocyte cells.

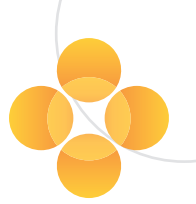
Secondary Melanoma

Secondary melanoma refers to an instance where the primary melanoma has spread or metastasised to other parts of the body.

Melanoma of Unknown Primary (MUP)

In a small number of patients a metastatic melanoma may be diagnosed without a primary lesion having occurred or being detected on the skin.





How is melanoma diagnosed?

If you have a skin lesion, spot or discolouration that is of concern to you, it is recommended that you consult a skin cancer professional. This could be your general practitioner or you might get a referral to a specialist.

Skin lesions that are suspected of being cancerous are investigated by your doctor and/or dermatologist via two principal methods: **dermatoscopy** and **biopsy**.

Dermatoscopy is the examination of the skin, a blemish or mole with a hand held tool called a **dermatoscope**. It gives excellent vision of the skin with magnification. The outer layer of our skin is transparent so that the dermatoscope allows the user to assess the patterns of the pigment in the deeper layers of the skin. Thus the examiner is able to see, without surgery, the underlying structures and colours of the lesion. The practitioner is interested in features such as asymmetry, the pigment pattern or 'network' and the presence of any blue-white discolouration.

If a skin lesion or mole appears suspicious under the dermatoscope, it is removed or a **biopsy** is taken for further pathology evaluation.

Biopsy is where a sample of tissue is taken from the suspicious skin lesion. This is sent to a pathologist who examines the tissue under a microscope, to determine its cellular properties. A partial biopsy is where the sample is taken by shaving the top layer of skin or by removing a sample of the lesion. An excisional biopsy is when the whole skin lesion is removed for further diagnosis. For pigmented lesions or when there

is a suspicion of a diagnosis of **melanoma** typically an excisional biopsy is performed so that the whole lesion can be examined to be sure the depth of tumour can be assessed. This is essential information if the lesion is a melanoma. In certain circumstances the doctor may consider a partial biopsy is appropriate. If the diagnosis is melanoma, there is no evidence that it is detrimental to have had a biopsy performed as the initial treatment.

Types of Melanoma

Melanoma is classified according to differences in the appearance and behaviour of the lesion. There are four different types of melanoma that can be described as follows:

- **Superficial spreading melanoma:** This is the most common form of melanoma representing roughly 70% of all cases. This type of melanoma undergoes a (superficial) growth phase called **radial** growth prior to invading deeper into the skin, reaching the dermis, and posing a threat of distant spread via the blood stream or lymphatic system. They can develop a vertical growth phase over time. Superficial spreading melanomas are typically characterised by having irregular borders and uneven pigmentation.
- **Nodular melanoma:** This is the most aggressive form of melanoma as it has a **vertical growth** phase from the outset. Nodular melanomas are typically characterised by being a raised, nodular lesion with irregular patches of colour and an irregular border. Up to 20% of these nodular melanomas may not have any pigment and this can make diagnosis more difficult.

- **Lentigo maligna melanoma:** Generally considered the least aggressive melanoma due to its long radial growth phase. Lentigo maligna melanoma is commonly found on older people who have worked in an outdoor occupation. These occur on areas of the body that have received a lot of sun exposure and are therefore most common on the face, ears, neck and head.
- **Acral lentiginous melanoma:** This melanoma has a short horizontal growth phase. Therefore, it is considered more aggressive than superficial spreading melanoma and less aggressive than nodular melanoma. This type of melanoma is found on the soles of the feet, on the palms or under the fingernails. It is the most common form of melanoma in Asians and black skinned people.

Progression of Melanoma

The **epidermis** is the outer layer of the skin and does not have blood vessels or lymphatics. Melanoma begins in **melanocytes** which are cells found in the lowest part of the epidermis. If the melanoma is contained in the epidermis when removed it is called “in situ” or “level I”.

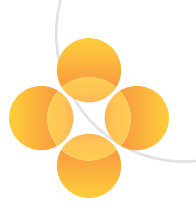
It should be cured with adequate removal at this stage.

Below the epidermis in the dermis, there are capillaries and lymphatics channels. If malignant cells make it into the capillaries and / or to lymphatics under the epidermis they can be washed into the blood or lymphatic system. Given time and unchecked, the malignant cells may migrate through blood vessel walls and form secondary deposits of tumour in distant sites. This is known as **metastasis**.

Malignant melanoma cells can also travel into the **lymphatic system**, which occurs in much the same way as blood-borne metastasis. In the case of lymphatic spread, the melanoma cells travel through the lymphatic system and can lodge in lymph nodes, which usually enlarge and become obvious to both patient and doctor. It is possible for the melanoma cells to grow in the lymph node and not grow elsewhere so that removal of the glands is still potentially curative, although the presence of the melanoma cells in the lymph nodes does increase the potential they may have spread to other parts of the body as well.

“I find it very difficult to say ‘I have Cancer because I don’t look any different - I don’t look sick, in fact I look very well – everyone keeps telling me! My family and friends think because I had the surgery that is the end of it all. I feel the implications of “Melanoma” is not understood and most people don’t realise it can spread to vital organs. They seem to think it is just a “skin thing”.

Barb OAM, MPA member



Confusion regarding levels and stages of Melanoma

One of the most common areas of confusion for melanoma patients is the difference between the Levels of Melanoma and the Staging of Melanoma. The Level of Melanoma relates to the depth of the melanoma in your skin (see Page 8 for a full overview) and the Staging of Melanoma refers to how limited or advanced the melanoma is at the time of diagnosis (see Pages 9-10 for more information). The higher the Stage of Melanoma you are diagnosed with, the further the melanoma has spread in your body. The Stage of Melanoma you are diagnosed with will be used by your treating doctor to develop your treatment plan - an earlier Stage may only require surgical removal, whereas later Stages may require surgery and more advanced treatments. These are explored in depth later in this Guide.

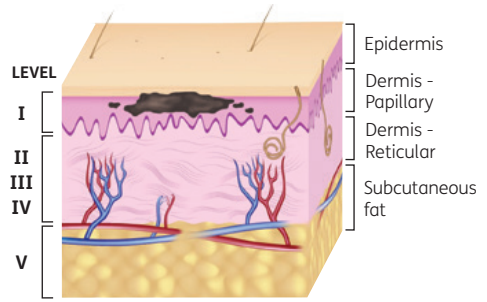
It is important to understand the difference between Staging and Levels of Melanoma. To avoid confusion between you and your treating doctors, you can ask your doctor to explain to you what Level of Melanoma you may have as well as what Stage of Melanoma you have been diagnosed with. For example, a Level 4 (or Level IV) melanoma is not the same as a Stage IV melanoma patient. The medical profession has starting using the diagnostic measurement called “Breslow Depth” to replace Levels as this is a more accurate measure to assist in the development of your treatment plan (see Diagram on Page 8 for more information about Breslow Depth).

If you are uncertain about the stage or level of your melanoma, it is okay to ask your treating doctor to explain your melanoma to you. The level and stage of your melanoma are a critical part of determining your treatment and care moving forward so it is important that you fully understand your diagnosis. This information will provide you with clarity to make informed decisions about your treatment, care and management moving forward.

Growth phases of Melanoma

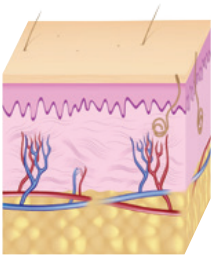
Cutaneous Melanoma (melanoma originating in the skin) grows and spreads in two phases, called the radial and vertical growth phases. During the **radial growth phase** melanoma grows horizontally across the surface of the skin. The risk of spread from the melanoma at this stage is low. The **vertical growth phase** occurs when the melanoma invades deeper into the layers of skin. The deeper the invasion the more dangerous the melanoma because of its ability to enter either the blood stream or lymphatic system and spread to distant parts of the body.

The Radial Growth Phase of Melanoma

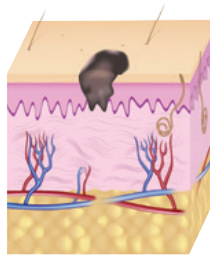


In Situ Melanoma

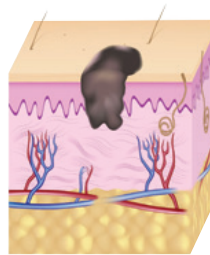
The Vertical Growth Phases of Melanoma



Undamaged skin



In early stages, melanoma spreads laterally across the top layer of the skin



As it grows deeper into the skin, it may become ulcerated



When the melanoma grows deeper, it reaches the blood vessels and lymph nodes of the dermis

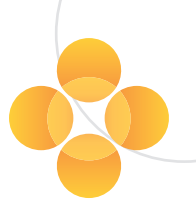
Breslow Depth

The pathologist measures, in millimetres, the thickness of the primary tumour. Breslow depth is measured starting at the outer layer of the epidermis downward to the deepest extension of the melanoma. It is more predictive of outcome (prognosis) than the Clark Level.

1mm = depth of a 5¢ piece

2mm = depth of 20¢ piece

4mm = depth of 2 x 20¢ pieces



Staging of Melanoma

Factors determining melanoma staging

Tumour Depth: How deeply the tumour has penetrated the skin. This is measured by using a microscope. The thickness is measured in millimetres. This is referred to as the 'Breslow Depth'. The thicker the tumour, the greater the chance it might have metastasised (spread) to regional lymph nodes or distant sites.

Tumour Ulceration: Ulceration of a skin tumour means that the epidermis (or top layer of the skin) that covers the melanoma is not intact. Ulceration may not be seen with the naked eye. Ulcerated melanomas pose a greater risk for metastatic progression.

Number of metastatic lymph nodes involved: If the melanoma has spread to the lymph nodes the risk of spread to other parts of the body is higher. The greater the number of lymph nodes containing melanoma, the less favourable the prognosis.

A sentinel node biopsy is a technique used to determine whether melanoma cells have spread

to lymph nodes at the time of diagnosis of the skin primary lesion. The procedure involves the injection of a radioactive tracer by a radiologist (in the radiology department), to show where the site and lymph node where the lymph fluid from the skin at the primary melanoma will flow. Afterwards, at the same time as the extra surgery for the primary melanoma a blue dye is injected around the site of the primary lesion. Using the guide from the radiologist a surgeon looks for the first lymph node to take up the dye. The lymph node is removed and sent to be examined by a histopathologist to determine if the node tests positive for melanoma. The procedure is considered when the Breslow thickness of the melanoma is more than 0.8mm.

Patients may develop lumps in the lymph node regions such as the neck, armpit and groin. This is lymph node metastasis.

Distant metastasis: Melanoma that has spread in the blood stream may grow in any site in the body.



Staging of Melanoma: Stage 0, I, II, III, IV*

STAGE 0

In **Stage 0** melanoma, the malignant cells are confined to the upper layer of the skin (epidermis or Level I). This means that the cancer cells are only in the outer layer of the skin (epidermis) and have not grown any deeper. The term for this is in situ, (which means 'in place' in Latin) or Level 1. There is no evidence the cancer has spread to the lymph nodes or distant sites.

STAGE I

Stage I melanoma is defined as a melanoma that is up to 2mm thick. There are two subclasses of Stage I: 1A (less than 0.8mm); 1B (0.8 -1mm or any melanoma less than 1mm with ulceration and melanoma 1-2mm without ulceration). There is no evidence the cancer has spread to lymph nodes or distant sites (metastasis).

STAGE II

Stage II melanoma. There are three subclasses of Stage II: IIA (1-2mm with ulceration and 2-4mm without ulceration); IIB (2-4mm with ulceration and more than 4mm without ulceration); IIC (more than 4mm with ulceration). There is no evidence the cancer has spread to the lymph nodes or distant sites (metastasis).

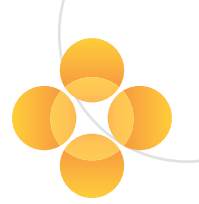
STAGE III

Stage III melanoma is defined by the presence of lymph node involvement combined with the thickness and ulceration in the primary skin melanoma. There are four subclasses of Stage III Melanoma: IIIA, IIIB, IIIC, IIID. The subclasses relate to the size and number of glands that contain the melanoma cells. There is no evidence the cancer has spread to distant sites (metastasis).

STAGE IV

Stage IV melanoma is defined when the melanoma has spread beyond the original site and regional lymph nodes to more distant areas of the body. The blood level of LDH (serum lactate dehydrogenase) in the patient may or may not be elevated. The significance of this is that it provides biochemical evidence of metastatic spread. The most common sites of metastasis are to vital organs (lungs, abdominal organs, brain, and bone), soft tissues (skin, subcutaneous tissues) and distant lymph nodes (lymph nodes beyond the primary tumour region).

*Staging of Melanoma is not to be confused with Clark Levels classification of Cutaneous Melanoma.



Treatment Options

Early Stage Melanoma - Treatment Options

For patients in stage 0, I or II, surgery of a primary melanoma includes, but may not be limited to, the removal of the primary tumour with a margin of normal skin.

Excision margins involve the removal of normal skin and flesh from around the primary tumour with the aim of ensuring any residual cancer cells have been removed. The margin of skin and fat relates to the thickness of the tumour. For a Level 1, in situ melanoma the margin should be 0.5 – 1.0 cm. For stage I–II melanoma the margin should be between 1–2cm.

Sentinel lymph node biopsy is considered in patients with Stage Ib – IIc primary melanoma.

The treatment of the primary melanoma will be influenced by the site of the original melanoma. For example, the treatment of a primary melanoma situated 3mm from a patient's eye would require different treatment to that of a melanoma situated on the back of a patient's leg. A skin graft or a skin flap may be required after the removal of the melanoma. After the surgery, a pathologist determines whether margins are clear by examining the entire specimen and the excised tumour edges.

Advanced Melanoma - Treatment Options

Surgery to remove lymph nodes

For patients with **stage III**, surgery is also the main treatment undertaken. The most common site for the lymph nodes to be removed is in the regions: neck; arm pit (axilla) and groin. A **removal** or **block dissection** of lymph nodes in the region surrounding the node/s that tested positive for melanoma is undertaken because there is a risk that there may be other nodes involved with melanoma that cannot be seen or felt. The pathologist helps to determine that the surgical margins are clear of the disease and the number of lymph nodes involved.

Radiotherapy

Radiation therapy is a localised treatment that uses high energy radiation to kill cancer cells. It does this by damaging the DNA of cells that are dividing. Radiotherapy is commonly used to relieve symptoms from metastases (secondary cancer that has spread from the first or primary site) from sites such as the brain, bones or lungs. Radiotherapy may be used as an alternative to surgery in patients

who are medically unfit for surgery or who cannot have the melanoma removed surgically because it is too extensive.

Adjuvant Systemic Therapy

When drugs are given to treat the whole person, it is called systemic therapy. These treatments work with the aim to treat the whole body and remove any cancer cells that may have escaped into the body. It is this disease that has the risk that it may appear as a recurrence of melanoma.

Treatment after surgery is called adjuvant therapy. The drugs can be in the form of oral therapy that targets a protein the melanoma expresses or immunotherapy, which is therapy that is designed to make your body's immune system recognise any residual cancer cell and act against them. Adjuvant therapy is designed to try and prevent melanoma recurrence and improve the survival beyond what surgery alone can offer.

The availability of these therapies and whether they are right for you, will be discussed with you by your treating team.

Chemotherapy

Chemotherapy is a systemic treatment that focuses on killing cancer cells by targeting rapidly dividing cells. Unfortunately, cancer cells are not the only rapidly dividing cells; the digestive system cells, hair cells and other healthy cells are also rapidly dividing cells. It is the damage to healthy cells that cause the

side effects from chemotherapy. Common side effects include hair loss, nausea, fatigue and effects on the bone marrow which normally has a high turnover of cells compared with the rest of the body. Chemotherapy is rarely used in Australia because of its limited efficacy in melanoma.

Immunotherapy & Targeted Treatments for Advanced Melanoma

Immune therapy

Immunotherapy treatments work by stimulating a patient's own immune system so that it can recognise and destroy cancer cells more effectively. These therapies modulate various components of the immune system.

Yervoy® (ipilimumab or “ipi”) is an immunotherapy which works with the body's immune system to treat cancer. It is also known as a checkpoint inhibitor.

Yervoy is an antibody that targets CTLA-4 expressed on T-cells. CTLA-4 acts like a “brake” on the immune system. By binding to CTLA-4, Yervoy releases the brake which allows the immune system to build its T-cell army to respond to cancer. T cells are white blood cells critical for the body's immune responses.

Sometimes, in this process, the T-cells may cause inflammation of healthy cells and may result in serious side effects. Side effects are generally manageable, if appropriately identified and treated.

Healthcare professionals use established guidelines to treat these side effects and the earlier the side effect is identified and treated, the better. It is important that patients tell their healthcare professionals about any side effects, even if they seem minor, as inflammation may cause serious damage to your body and some inflammatory conditions may be life-threatening.

Common sites of inflammation include the skin (itchiness and rashes), the liver (causing liver enzymes to increase) and the bowel and stomach (causing diarrhoea).

Yervoy treatment consists of four infusions administered every 3 weeks (i.e. over 10 weeks) through an intravenous infusion (i.e. a drip).

Yervoy is listed on the Pharmaceutical Benefits Scheme (PBS) for advanced melanoma and maybe given in combination with one of the other immunotherapies.

Keytruda (pembrolizumab) Keytruda is an immunotherapy which works with the body's immune system to treat cancer. Keytruda works by blocking a pathway that allows tumours to remain hidden from the immune system This helps to increase the ability of the body's immune system to detect and fight tumor cells. Keytruda is also known as a checkpoint inhibitor.

Checkpoint inhibitors like Keytruda work by blocking the interaction between PD-L1 (a protein found on the surface of tumor cells) with PD-1 (a receptor found on immune cells). Blocking the PD-1/PD-L1 connection allows a patient's immune system to recognize and kill cancer cells.

Keytruda targets PD-1 and it works by “disarming” the tumour's defences that block the the ability of T cells (white blood cells critical for the body's immune responses) to attack the tumour.



Immunotherapy & Targeted Treatments for Advanced Melanoma *continued*

Keytruda is administered intravenously every 3 or 6 weeks.

Keytruda is generally well tolerated but common side effects include fatigue and joint pain. Inflammation of major organs including intestines, lungs and liver can also occur. It is important that patients tell their healthcare professionals about any side effects, even if they seem minor as inflammation may cause serious damage to your body and some inflammatory conditions may be life-threatening.

Keytruda is listed on the Pharmaceutical Benefits Scheme (PBS) for first line treatment of unresectable Stage III or IV melanoma regardless of BRAF mutation.

As of the 01 September 2020, Keytruda has been listed on the PBS as an adjuvant therapy for resected Stage III melanoma patients.

Opdivo® (nivolumab or “nivo”) Opdivo is an immunotherapy which works with the body’s immune system to treat cancer. Opdivo works by blocking a pathway that allows tumours to remain hidden from the immune system. This helps to increase the ability of the body’s immune system to detect and fight tumor cells. Opdivo is also known as a checkpoint inhibitor.

Checkpoint inhibitors like Opdivo work by blocking the interaction between PD-L1 (a protein found on the surface of tumor cells) with PD-1 (a receptor found on immune cells). Blocking the PD-1/PD-L1 connection allows a patient’s immune system to recognize and kill cancer cells.

Opdivo targets PD-1 and it works by “disarming” the tumour’s defences that block the ability of T cells (white blood cells critical for the body’s immune responses) to attack the tumour.

Opdivo is administered intravenously every 2 or 4 weeks.

Opdivo is generally well tolerated but common side effects include fatigue and joint pain.

Inflammation of major organs including intestines, lungs and liver can also occur. It is important that patients tell their healthcare professionals about any side effects, even if they seem minor as inflammation may cause serious damage to your body and some inflammatory conditions may be life-threatening.

Opdivo is listed on the Pharmaceutical Benefits Scheme (PBS) for all resected Stage III patients, regardless of BRAF mutation.

Combination Treatment - Yervoy (ipilimumab) and Opdivo (nivolumab) in combination.

Opdivo and Yervoy target different checkpoint pathways (PD-1 and CTLA-4) to boost the immune system’s response to cancer.

When used together, they have a complementary effect. In summary, Yervoy builds the T-cell army and Opdivo unleashes the T-cell army against the tumour.

Sometimes, in this process, the T-cells may cause inflammation of healthy cells and may result in serious side effects. (See Yervoy and Opdivo side effects.) More people experience serious side effects when treated with the combination of Opdivo and Yervoy than single agent treatment. Side effects are generally manageable, if appropriately identified and treated. Healthcare professionals use established guidelines to treat these side effects and the earlier the side effect is identified and treated, the better. It is important that patients tell their healthcare professionals about any side effects, even if they seem minor, as inflammation may cause serious damage to your body and some inflammatory conditions may be life-threatening.

When used in combination:

- Opdivo and Yervoy are administered together for the first four treatments, every 3 weeks (ie four treatments over 10 weeks)

Immunotherapy & Targeted Treatments for Advanced Melanoma *continued*

- Opdivo is then administered on its own every 2 or 4 weeks
- Treatment is stopped if the cancer progresses or there are unacceptable side effects.

The combination Yervoy and Opdivo is listed on the Pharmaceutical Benefits Scheme (PBS) as a first-line treatment for melanoma patients with advanced disease who are BRAF positive.

Imlygic® (Talimogene Laherparepvec or Tvec) is a genetically modified live oncolytic herpes virus designed to replicate within cancer cells and produce an immunostimulatory protein called GM-CSF (granulocyte-macrophage colony-stimulating factor).

Imlygic is injected directly into the melanoma tumour, causing cell lysis, or death, which ruptures the tumours, and releases tumour-derived antigens, which along with GM-CSF, may promote an anti-tumour immune response. However, the exact mechanism of action is unknown. Imlygic is a live virus in patients and due to difficulties with importation, storing and administration it is not available in Australia.

Targeted Therapies

Melanoma is one of the cancers with the highest frequency of genetic mutations. There are several genetic mutation tests available and identifying if your tumour has a mutation, it can be important in determining your treatment pathway. The genetic tests are performed on a tumour sample from a biopsy.

Mutations can result in abnormal signalling (in the MAPK pathway) which can stimulate the growth of melanoma cells.

Mutated signalling pathways in melanoma cells are targets for therapy.

If no mutation is found the tumour is referred to as “wild type”, meaning no specific gene mutation has been identified in the melanoma tumour.

BRAF is a protein found in the cells of your body. It is important for normal cell growth. BRAF is turned on by a special chemical signal. In your melanoma, the BRAF protein has a mutation which means it is ‘on’ all the time. This results in abnormal cell growth and may have led to the development of your melanoma.

The BRAF mutation is found in approximately half of all melanomas and is the most common genetic mutation associated with melanoma. There are several forms of BRAF mutations including V600E, V600K, V600D, V600G and V600R.

NRAS is the second most common mutation found in advanced melanoma found in 10-12% of melanomas.

These tumours tend to be thicker and grow faster.

c-KIT mutations are most commonly found in Asian populations. They are also more likely to be found in melanomas that start on the palms of the hands, soles of the feet, under nails, inside the mouth and nose, or other mucosal areas.

Approximately 40-45% of melanomas have BRAFV600 mutations. In these patients targeted therapies (oral therapies that turn the BRAF mutation off) can be used to block uncontrolled signals and slow down the rate of tumour growth.

Tafinlar (dabrafenib) and **Mekinist (trametinib)** are targeted treatments used in combination for those with the BRAFV600 mutation.

They are both protein inhibitors and target the pathways that allow tumour growth, slowing down cell growth and division.

Tafinlar and Mekinist used in combination form a double blockade and the combination of the two inhibitors (BRAF inhibitor and MEK inhibitor) has shown significantly improved survival and delayed drug resistance over the use of a single agent.



Immunotherapy & Targeted Treatments for Advanced Melanoma *continued*

This treatment combination is taken orally (in pill form) each day.

Tafinlar and Mekinist can cause side effects. The most common side effects are fever and fatigue. Diarrhoea, nausea, vomiting, skin rash, swelling of ankles or feet and eye problems are uncommon.

The combination of Tafinlar and Mekinist is listed on the Pharmaceutical Benefits Scheme (PBS) for the treatment of BRAFV600 mutation-positive unresectable metastatic melanoma and has now been made available as an adjuvant therapy following regional lymph node surgery for patients with stage III B, IIIC and IIID melanoma

Zelboraf (vemurafenib) and **Cotellic (cobimetinib)** are treatments used in combination for those with the BRAFV600 mutation.

They are both protein inhibitors and target the pathways that allow tumour growth, slowing down cell growth and division.

Zelboraf and Cotellic used in combination form a double blockade and the combination of the two inhibitors (BRAF inhibitor and MEK inhibitor) has shown significantly improved survival and delayed drug resistance over the use of a single agent.

Zelboraf and Cotellic can cause side effects. The most common side effects include sunburn or sun sensitivity, skin rash. Blistering, swelling of the face, hands, or soles of the feet, joint discomfort and eye problems are less common.

This treatment combination is taken orally (in pill form) each day.

The combination of Zelboraf and Cotellic is listed on the Pharmaceutical Benefits Scheme (PBS) for the treatment of BRAFV600 mutation-positive unresectable metastatic melanoma.

Braftovi (Encorafenib) and **Mektovi (Binimetinib)** Braftovi and Mektovi are treatments used in combination for those with the BRAFV600 mutation.

They are both protein inhibitors and target the pathways that allow tumour growth, slowing down cell growth and division.

Braftovi and Mektovi used in combination form a double blockade and the combination of the two inhibitors (BRAF inhibitor and MEK inhibitor) has shown significantly improved survival and delayed drug resistance over the use of a single agent.

This treatment combination is taken orally (in pill form) each day.

Braftovi and Mektovi can cause side effects. Fatigue, loss of appetite and nausea are common side effects, less common but important side effects can include fever, diarrhoea and abnormal liver function. It would be uncommon to experience side effects affecting your vision or heart but speak to your doctor if concerned.

The combination of Braftovi and Mektovi is listed on the Pharmaceutical Benefits Scheme (PBS) for the treatment of BRAFV600 mutation-positive unresectable metastatic melanoma.





Clinical Trials

What is a clinical trial?

Clinical trials are medical research studies that aim to find a better way to manage a particular disease. The purpose of a clinical trial is to evaluate new approaches to learn how people respond to them and what side effects might occur as a result. Clinical trials are considered to be part of best practice medicine and are one of many options for treatment of a disease or illness.

Different kinds of clinical trials are available to health consumers.

Some of these include:

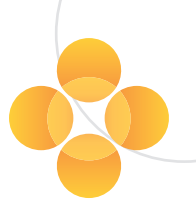
Treatment trials: These involve trials of experimental treatments, drugs or new approaches to surgery or radiation therapy.

Prevention trials: These consider new ways to prevent disease. They are usually less invasive and may include medicines, vaccines, vitamins or changes to lifestyle or behaviour.

Diagnostic or screening trials: These involve evaluating tests or procedures for diagnosing and detecting diseases or conditions.

“When my doctor suggested a clinical trial all I could think was “I don’t want to be a guinea pig” but once the process was explained to me and I understood the details of the trial I felt that I was making an informed choice about my care. Being on a clinical trial has offered me greater treatment options and I feel I am giving myself the best chance of a better outcome.”

Jane, MPA member



Why are clinical trials important?

A clinical Trial is a reliable, controlled way to find out the effects of different treatment that is designed to find out if a new treatment more effective than current standard treatment, and to identify potential risks and side effects. A new treatment will only become the new standard after it has been proved

effective and safe in clinical trials, and shown to be better than other treatments. The significant improvements seen with both targeted and immunotherapy over the last decade has only been possible through clinical trials into the treatment of melanoma.

The possible advantages and risks of participating in a clinical trial

You will need consider if a clinical trial is something you want to do. You may find it helpful to speak with your family, friends, other patients and organisations (like MPA). It is always advisable to speak with your treating doctors about your

situation before making any decisions (see further information below). It is important that you understand the possible advantages and risks that can be associated with clinical trials:

ADVANTAGES

- Active role in your own health care.
- In a randomised trial there are generally two types of treatments being compared:
 - the standard treatment (the best available treatment for your cancer),
 - the new trial treatment (the intervention treatment).
- You cannot assume the new treatment is better than the standard treatment.
- Closer disease/health monitoring.
- You can help in the future treatment of people with cancer.
- You may access new treatments before they are available through government support.

RISKS

- The new treatment may be less effective than standard care.
- Even if the new treatment is effective, it might not work for you.
- You may experience unexpected side effects.
- You may need to travel to the hospital more often.
- You will need to read a lot of information and sign paperwork.
- You may not hear the results of the trial, or you may see them in the media before being told.

How do you enter a clinical trial?

There are strict inclusion and exclusion criteria about who can and cannot participate in a trial and this is usually determined giving consideration to the safety of trial participants, as well as the research question/s that the trial is trying to answer. The common criteria that are assessed before a patient can enter a trial are:

- **Type of cancer**
- **Stage and extent of cancer:** the trial may only be relevant to patients with a certain

stage of melanoma, or exclude patients who have metastases.

- **Previous treatment for cancer:** participants may have had to have received a treatment/s or had no treatment at all.
- **Other health problems:** do you suffer from any other conditions that might prevent you from enrolling in the trial?
- **Performance status:** how are you responding to your treatment currently? Does your treating doctor/s feel you are able to participate in a trial?

ALWAYS TALK TO YOUR TREATING DOCTOR AND/OR ONCOLOGIST FIRST ABOUT YOUR SUITABILITY FOR A CLINICAL TRIAL.

Your treating doctors will be able to advise you on how to locate a clinical trial and whether you will be eligible to enter a clinical trial. It is important that you research all of your available treatment options, including clinical trials, and work with the medical team managing your melanoma in working out the best way forward for you. Some questions that you might want to ask about clinical trials and whether you should participate in a clinical trial are:

1. What is the usual treatment for my condition?
2. What is the purpose of this trial?

3. Is this trial appropriate for me?
4. Are there choices other than the trial and standard treatment?
5. What makes me eligible (or not)?
6. What are the possible benefits and risks?
7. What are the usual costs associated with involvement?
8. Will I get to see the results?

Remember, it's okay if you change your mind. You can withdraw from a clinical trial at any time. It is not necessary to give a reason. If you do decide to withdraw from a trial, there is no disadvantage to you in the care you receive as you will be able to receive the standard treatment, or the most appropriate treatment for you.

For further information

www.melanomapatients.org.au

Visit our website for fact sheets, web links and details of support in your area.

Clinical Trials:

AUSTRALIA AND NEW ZEALAND MELANOMA TRIALS GROUP

www.anzmtg.org

The ANZMTG co-ordinates and conducts quality research for melanoma control. They also develop and undertake melanoma studies in collaboration with researchers and health care professionals, support networks and consumers.

AUSTRALIAN CANCER TRIALS

www.australiancancertrials.gov.au

This is a free information service that displays the latest clinical trials in cancer care, including trials that are currently recruiting new participants. Information is collated from

the Australian New Zealand Clinical Trials Registry and www.clinicaltrials.gov from the United States.

AUSTRALIAN CLINICAL TRIALS

www.australianclinicaltrials.gov.au

This website aims to provide reliable and up-to-date information and advice about clinical trials in Australia for the public, researchers and industry. For the public, the website provides easy to understand information about clinical trials in Australia and how to become involved in a clinical trial.

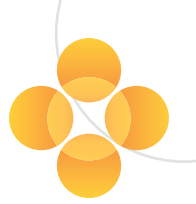
CANCER TRIALS AUSTRALIA

www.cancertrialsaustralia.com

Cancer Trials Australia is a clinical trial network that provides a fully comprehensive oncology clinical trial service.

CONSUMERS HEALTH FORUM OF AUSTRALIA

www.chf.org.au/clinical-trials-keydocs.php



Post Treatment

Each individual's treatment plan will be different as this is dependent on the location, stage, and type of melanoma that you have been diagnosed with.

Consequently, your post treatment requirements will vary depending on your treatment journey.

Some issues that you may encounter post treatment include, but are not limited to:

- > Scarring
- > Pain
- > Lymphoedema
- > Emotional and Psychological issues such as depression and anxiety
- > Long term side effects of treatment

It is also vitally important that you continue to regularly undertake self skin examinations to monitor any new changes on your skin. Additionally it is recommended that you undergo professional skin checks under the care and management of your treating medical practitioner.

Many people who have had melanoma become fearful that their own family and friends are at risk of getting melanoma. This is normal. If you feel these concerns, speak to your family about how they can care for their own skin and advise them to visit their doctor for a regular skin check. You can also contact MPA directly for support and assistance.

It is important that following diagnosis and treatment for melanoma that you continue to adopt behaviours to reduce your risk of recurrence. You must still take precautions when out in the sun, including wearing sun safe clothing, applying sunscreen, wearing a hat, seeking shade, minimising UV exposure (including not using sun beds) and wearing appropriate eye wear. Additionally, it is important that you undergo regular skin examinations with your treating doctor who will be able to assist you in monitoring your skin for any changes or suspicious lesions, as well as ensuring you do not develop any enlarged lymph nodes or unusual lumps/swelling or other symptoms that may be related to melanoma. Remember, it is vital that you are proactive in managing your own care and being sensible in monitoring your own body – if detected early, a melanoma can be effectively treated and managed.

Most of all, be kind to yourself. Eat a healthy diet and participate in regular physical activity. Try to keep perspective on your situation by incorporating strategies into your everyday life that help you manage any melanoma related issues that you may now have following treatment, and don't be afraid to ask for help if you need it. MPA offers many effective peer to peer support services that may help you to talk to another patient who may be experiencing similar issues to you.

For further information

www.melanomapatients.org.au

Visit our website for fact sheets, web links and details of support in your area.

AUSTRALIAN CANCER SURVIVORSHIP CENTRE

Visit our website for fact sheets, web links and details of support in your area.

BEYOND BLUE

www.beyondblue.org.au 1300 224 636

LIFELINE

131 114 (24 hours, Australia wide)

KNOW YOUR OWN SKIN

www.knowyourownskin.com.au

Lymphoedema

What is Lymphoedema?

Lymphoedema is a swelling that may occur after the surgical removal of lymph nodes or radiation to nodes affected by melanoma. Lymph nodes are in your armpits, groins, abdomen, chest and neck. They filter out harmful bacteria and assist in the body's response to infection. When they are removed or damaged the movement of lymph fluid around that area is obstructed, which could lead to lymphoedema.

About 25% of people who have their lymph nodes removed will develop lymphoedema, but early detection and intervention can help control it.

Lymphoedema may occur in the limb or body area nearest your surgery or radiotherapy at any time, usually within the first 12 months, but it can develop years after treatment. Lymphoedema is permanent and progressive but it can be controlled. You might notice a slow increase in symptoms like aching, heaviness, tightness or swelling in the body part near the damaged lymph nodes. Removal of lymph nodes in the armpit may result in swelling in the arm or chest on the same side or, if removed from the groin, the leg or lower trunk may be affected.

Things that may affect the risk of developing swelling after treatment include infection, being overweight or obese and lack of use of the arm or leg. It is important to note that the lack of lymph fluid movement can lead to infection. If you have lymphoedema you are at risk of developing the skin infection, cellulitis. Signs of cellulitis include redness, painful swelling, warm skin and fever. If you think you have an infection attend your emergency department immediately, as IV antibiotics are usually the best treatment.

Treatment

Management of lymphoedema may include:

- > Massage (manual lymphatic drainage),
- > Exercise,
- > Skin care – keep your skin healthy, moist and unbroken
- > Compression therapy (bandaging and/or compression garments)
- > Low level laser therapy,
- > Other electrical or vibratory stimulation
- > Surgery

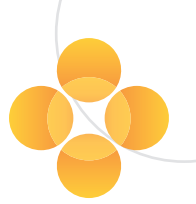
The most important component of lymphoedema treatment is self-management, which you should develop in partnership with your treating practitioner.

All treatment is aimed at improving the flow of lymph fluid through the affected area. This will help reduce swelling and keep the tissue in that area healthy. Reducing the swelling will lower your risk of infection, improve your wellbeing and make movement easier.

You will be encouraged to exercise and elevate your affected limb. There are specific exercises designed to help the lymph fluid move and daily self-massage is very important. Some people will be advised to wear a compression stocking or sleeve. Other people with more advanced lymphoedema will require complex lymphoedema therapy such as manual lymphatic drainage, compression therapy, laser treatment and surgery to help with drainage.

Practitioners

Some hospitals have lymphoedema clinics or physiotherapists and OT's who are trained to treat lymphoedema who you can see if you have had treatment in that hospital. Ask your melanoma nurse, or, if there is not a melanoma nurse in your hospital ask to speak to the breast cancer nurse who will have information about lymphoedema management.



The Australian Lymphology Association has a list of reliable and knowledgeable practitioners (these can be physiotherapists or occupational therapists who use massage, laser therapy and other therapies or massage therapists) around Australia.

Some private health funds help with the cost of lymphoedema treatment and Care Plans can be used to help with the cost of lymphoedema treatment – speak to your GP.

Compression Garment subsidies and treatment costs

All states and territories in Australia, except SA, have some form of compression garment subsidy.

Private health insurance schemes may pay part of the cost – it is recommended that you provide them with a letter from your practitioner explaining why you need to use the garment.

To find a treating practitioner

AUSTRALIAN LYMPHOLOGY ASSOCIATION

www.lymphoedema.org.au/the-register/find-a-practitioner/

Compression garment subsidy information

www.lymphoedema.org.au/about-lymphoedema/compression-garmentschemes/

Melanoma: Awareness, Prevention, and Early Detection.

Genetic risk factors and testing

There are a number of genes that are associated with melanoma risk, particularly if there is a family history of melanoma. If there are a number of directly related (first degree) relatives, typically more than one, and/or a number of relatives in the family who have had multiple primary melanoma, or had early age of onset (< 40 years) there is a strong chance there may be a genetic predisposition.

However, there are uncertainties with respect to the degree of the risk that exist for an individual and, as well, genetic testing is unlikely to change the management, which will be careful, regular skin/mole examination. Thus specific tests for gene changes has limited value and tends to be performed in selected cases where the family risk is well known.

Vitamin D

1. What health outcomes are influenced by vitamin D?

Vitamin D is important for overall bone health and helps to regulate the immune system. There is a range of research underway to better understand the role that vitamin D plays in a range of health issues including; diabetes, mental health, cancer and multiple sclerosis, however, the results are unclear at this stage. Vitamin D is produced by the body through exposure of the skin to small amounts of sunlight. Vitamin D can also be obtained through the consumption of certain foods such as vitamin D fortified milk and dairy products and fatty fish along with oral vitamin D supplements.

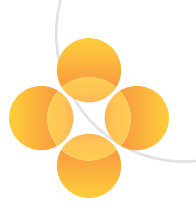
2. How do I balance getting sufficient vitamin D with protecting my skin from the sun?

Most people will get the vitamin D they need from incidental UV exposure from everyday outdoor activities and the foods they eat. Australian studies have shown that normal use of skin protection measures such as sunscreen, clothing, hats and sunglasses, in combination with a healthy active lifestyle, does not generally result in vitamin D deficiency for most people. (Kimlin et al 2014 - <https://www.ncbi.nlm.nih.gov/pubmed/24573539>)

3. Should I have my vitamin D levels checked?

Vitamin D levels will change due to a range of factors such as age, skin type, body mass index, season and geographical location along with illness. If you are concerned about your vitamin D level, talk to your doctor to see if a blood test is right for you and your Doctor will assist in how to interpret your results.





Ocular Melanoma

There are two types of melanoma that occur as a primary melanoma in the eye, uveal (choroid, iris and ciliary body) and conjunctival melanoma. Both types are uncommon.

Uveal melanoma: When treating patients the aim is to conserve the eye. The use of a plaque which emits radiotherapy to the melanoma is the most common treatment. The results from this treatment have a similar chance of controlling the primary ocular melanoma when compared with surgery for most tumours. Other treatments that maybe recommended depending upon the site and extent of melanoma include: observation with regular examinations; thermal therapy; charged particle radiotherapy; local tumour removal and removal of the eye.

The chance of cure for this type of ocular melanoma has not changed over 25 years.

Conjunctival melanoma: Once again there is a trend to use eye-conserving treatment. Local removal of the melanoma is the most common treatment. Alternative treatments or in possibly used in combination with surgery are: topical chemotherapy and or radiotherapy.

The management of ocular melanoma is complex and should be conducted in specialised units where eye-conserving therapies are available.



Carer and Support Information

Unpaid family carers provide care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged.

Unpaid family carers are a vital part of a melanoma patient's journey. Your carer may be a family member - such as your spouse, partner, child, parent, grandparent or sibling - or you may have a friend who has stepped into this role. You may have more than one carer.

Caring for someone who is unwell can be physically challenging and there is often little "down time" for carers to have a break or to socialise in the same way as others. It is common for a carer to always be thinking of the person for whom they care. It is very important that carers look after their health and well-being.

Because of the often constant demands made upon unpaid family carers it is important to make sure that your carer is supported. It is vitally important

that carers take care of themselves - as the old adage states "care for yourself in order to care for another". There is information and support services to assist your carer in their caring role.

Unpaid family carers can be a full time job in itself, yet many carers work in paid employment while also fulfilling the role of carer. It is important that you, or your carer, seek assistance to determine your eligibility for financial support (such as Centrelink payments) or access to funds through other means - such as paid leave from employer or your superannuation fund. Melanoma Patients Australia can provide you with referral information to assist you in making sure you access your full entitlements - contact details are below.

For further information

www.melanomapatients.org.au

Visit our website for fact sheets, web links and details of support in your area.

CARERS AUSTRALIA

Carers Associations offer information and services to unpaid family carers. You may contact your nearest Carers Association.

www.carersaustralia.com.au

1800 242 636

COMMONWEALTH RESPITE AND CARELINK CENTRES

Assists carers with information about respite.

www.commcarelink.health.gov.au

1800 052 222

CENTRELINK

Contact to determine eligibility for Carer Payment and/or Carer Allowance.

www.humanservices.gov.au

132 717

COMPANION CARD

Allows a person requiring the support of a carer to obtain free entry to events and organisations for their carer on the purchase of a full priced ticket.

www.companioncard.gov.au



“It has changed my life perspective totally. There is hope but be vigilant and agitate.”

Thomas, MPA member

Complementary and Alternative Medicines

When faced with a serious and life threatening diagnosis, many people turn to non-conventional therapies and medicines to assist them in their journey of recovery and survival.

Broadly speaking, complementary and alternative medicines (or CAMs) represents a huge variety of therapies that are considered outside the scope of mainstream medicine. CAMs may include the use of dietary supplements, naturopathic medicines, homeopathy, traditional Chinese medicines and much more. Complementary medicines are typically used in conjunction with conventional treatments whereas alternative medicines are generally used in place of conventional treatments.

After being diagnosed with melanoma, it is important that you explore all treatment options and determine a treatment plan that is right for you based on a fully informed decision. Some CAMs may claim to help fight cancer, improve the body's immune defence, prevent cancer progression or alleviate symptoms from

chemotherapy or radiation therapy. However, some CAMs may actually decrease the effectiveness of some cancer treatments and potentially worsen their side effects. Therefore it is imperative that if you are currently using CAMs or intend to use CAMs whilst receiving treatment for melanoma that you discuss this with your doctor and pharmacist.

In addition to this, your pharmacist will have access to further resources and can assist you in making a fully informed decision about your medicines.

“Positive thoughts and stories can help relieve stress of the diagnosis and give hope of a full recovery.”

Darrick, MPA member

For further information

www.melanomapatients.org.au

Visit our website for fact sheets, web links and details of support in your area.

CANCER COUNCIL AUSTRALIA

www.cancer.org.au

NATIONAL CENTRE FOR COMPLEMENTARY AND ALTERNATIVE MEDICINES

www.nccam.nih.gov

OFFICE OF DIETARY SUPPLEMENTS

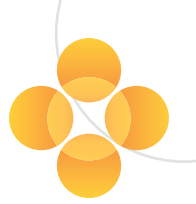
www.ods.od.nih.gov

**NATIONAL PRESCRIBING SERVICE
MEDICINES INFORMATION (NPS)**

1300 MEDICINE (1300 633 424)

POISONS INFORMATION CENTRE

131 126



Palliative Care

What is Palliative Care?

The focus of palliative care is to **improve quality of life** for the patient, their family and carers. Palliative care is appropriate for people in all disease stages, including those undergoing treatment, those living with chronic diseases and those nearing the end of life. A range of health professionals including the General Practitioner (GP) may deliver care. A team approach may be used to address physical, emotional, social and spiritual concerns that arise with advanced illness.

What does Palliative Care do?

Palliative care focuses on **helping people live well** by providing relief from physical symptoms such as pain and nausea, and by providing support with the psychosocial issues that arise from the diagnosis of a life threatening illness – whatever the prognosis. Palliative care also provides support for the patient's loved ones and carers during treatment, and where available grief and bereavement support may be provided.

Palliative care is **provided on a needs basis**, which means not every person diagnosed with melanoma will require palliative care in the same way. Some patients may not require palliative care at all; others may have ongoing treatment and palliative care at the same time; and others may receive palliative care only when they are nearing the end of life.

Who delivers Palliative Care?

A range of health professionals may be involved in delivering palliative care. These health professionals work together as part of a multidisciplinary team. The care team may include:

- > General Practitioners (GP's),
- > Specialist palliative care doctors and nurses,
- > Specialist doctors including medical and radiation oncologists,
- > Nurses,

- > Allied health professionals including pharmacists, physiotherapists, psychologists, dieticians and occupational therapists,
- > Social workers,
- > Pastoral care workers,
- > Grief and bereavement counsellors, and
- > Volunteers.

Access to Palliative Care

The patient may request a referral to a palliative care service or the patient's treating team, such as the medical/radiation oncologist, may suggest referral to a specialist palliative care team. In some cases chemotherapy and radiation may be provided as palliative treatment. Palliative care is provided in a range of settings. Patients with few symptoms may receive palliative care as part of their regular consultations with their GP or treating team. Where the patient may be nearing the end of life, palliative care can be provided in the patient's home or the patient may choose to move into care with professional providers. Care is available through paid private providers, hospitals, hospices as well as charitable organisations. Your treating specialists can advise you on the best options available for you.

For further information

www.melanomapatients.org.au

Visit our website for fact sheets, web links and details of support in your area.

PALLIATIVE CARE AUSTRALIA (PCA)

www.palliativecare.org.au/

On the PCA website you will find the National Service Directory – an online searchable directory of palliative and end of life care services across Australia, as well as links to state and territory palliative care organisations who can provide you with information about local support and services.

Take Control of Legal Issues

This chapter will help you to:

- Understand what your legal rights are to gain access to superannuation and insurance.
- Take steps to protect your assets for the benefit of your family.
- Cope with changes in the workplace.

Introduction

When first diagnosed with any major illness, particularly one which is permanent and life altering, legal issues are often the last thing considered.

Unfortunately neglecting your legal rights and options to protect you and your family too often make those daunting legal issues more complicated.

There are some simple steps you can take now to ensure you have access to any financial support you may need and also to ensure that in the future your family are taken care of even if you are unable to work or provide for them.

Accessing Superannuation and Insurance

All working Australians have a superannuation fund to which their employer must contribute amounts during the course of their working life. Some people also elect to contribute further to their super personally.

You can access your superannuation before retirement age in the event of serious injury or illness. All superannuation funds also have a component of insurance which is there to help you in the event you are unable to work because of serious illness or injury.

All policies are different. Some funds will offer lump sum benefits in the event that you become totally and permanently disabled or partially and permanently disabled. Some funds will even provide temporary cover if you are off work for

only a short period of time by paying all or a percentage of your income whilst you are unable to work. Superannuation funds also additionally come with a terminal illness or death benefit on a member being diagnosed or dying.

The terms and conditions applying to these insurance components are sometimes straight forward but often more complex than they look.

You should contact your superannuation fund to find out what entitlements you may have. You should critically analyse the information you are given by the superannuation fund manager or insurer. Because of the complexities involved and the different considerations that apply in your own different circumstances a one size fits all approach often means that some people will fall through the cracks.

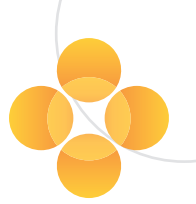
To ensure that the information you receive is correct and to assist you with pursuing a claim for your entitlements you should seek legal advice.

You do not need to show fault on the part of anyone or that the cause of your illness was beyond your control. Generally the mere fact of having the illness and that it stops you from working is all that has to be shown.

Benefits are generally available for people of working age. Different funds have different rules and you should check your own circumstances.

“By talking to a lawyer I was able to make sure I had the appropriate levels of insurance in case I needed time off work or my melanoma got worse. I was able to put in place the right documents to protect me and my family. I wanted to make my own choices about my own care while I could. I am glad I took control of things myself and didn’t leave it too late.”

Bill, MPA member



Protecting your Assets and Family

Wills

It is essential that your intentions regarding distribution of property as well as your wishes in relation to the continuation of treatment are known and documented.

A will is a document which identifies your intentions and provides instructions as to the distribution of your assets when you die.

Depending on their relationship to you family members will accrue rights under the will or in accordance with the law and sometimes those rights can conflict. Having a clear and up-to-date will is essential to avoid any conflict.

Whenever your personal circumstances change you should review and if necessary update your will.

The way in which assets are passed via a will can impact on the beneficiary of those assets. Development of appropriate testamentary trusts will assist the beneficiaries access those assets and assist with tax minimisation.

Testamentary discretionary trusts may be particularly useful if the beneficiary who will receive the assets:

- > has a disability,
- > is poor at handling his/her finances,
- > practices in a profession which has a high risk of litigation,
- > is in a high tax bracket,
- > has a history of bankruptcy.

In the event of conflict between beneficiaries or potential beneficiaries of an estate there are often significant emotions at play. The complex rules applying to the passing of assets via a loved ones estate mean that you need to have a skilled and compassionate lawyer to assist you in either defending or enforcing your entitlement.

Good planning and open communication by a loved one prior to their death will often avoid conflict or confusion.

Enduring Powers of Attorney and Advanced Health Directives

When you are fighting an illness or significant injury you will often find that you cannot or simply do not have the capacity to make decisions on your own behalf. In these worrying circumstances family members may not know what your wishes are in relation to treatment or what is best for you.

In all states of Australia there is the ability to document an Advanced Health Directive or instructions for your loved ones as to your wishes in the event that you lose capacity to make decisions because of an injury or illness or while undergoing treatment.

An Advanced Health Directive can look at issues including:

- > what level and extent of treatment you wish to undergo,
- > who should have the power to make decisions on your behalf,
- > special medical conditions that your doctor or other medical staff should know about,
- > religious, spiritual or cultural beliefs that may affect treatment,
- > considerations in relation to resuscitation or the withholding or withdrawing of life sustaining measures, and
- > your wishes in relation to the donation of organs in the event of your death.

In combination with an Enduring Power of Attorney an Advanced Health Directive will ensure your wishes are met and maintained throughout the course of your battle with this illness.

An Enduring Power of Attorney appoints a responsible and trusted person to make decisions on your behalf. An Enduring Power of Attorney remains in force even when you lose capacity to make decisions on your own.

Coping with Changes in the Workplace

When you suffer a serious illness it often affects your ability to attend work or your ability to undertake your work duties.

All employees are entitled to some measure of sick or unpaid leave in the event of a serious illness.

The sources of this entitlement are many and varied and can range from legislation through to written contracts of employment.

Whether you are any employee, an independent contractor or in business a serious illness should not be used by an employer or head contractor as an excuse to disadvantage you or treat you differently.

There are general protections available to you in the workplace in the event that you suffer an illness or injury and need to access leave or have some reasonable adjustment undertaken to enable you to continue to work.

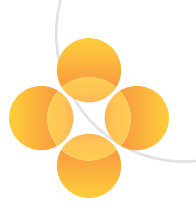
An employer cannot treat you unfairly or take adverse action against you merely because you have suffered an injury or illness or are attempting to exercise a workplace right like taking sick leave. If an employer does take adverse action in these circumstances you are entitled to claim compensation and ancillary orders to restore the status quo as well as requesting that the employer be subject to a fine for breaching legislation.

Anti-discrimination laws across Australia recognise that people with illnesses and injuries are at a disadvantage and should be treated fairly. An employer must make reasonable adjustment in the workplace to assist you to conduct your work duties to the best of your ability having regard to the impacts of your injury or illness.

If you feel you have been treated unfairly then you should seek legal advice.

For more information please visit
www.melanomapatients.org.au

“...ensure that in the future your family are taken care of even if you are unable to work or provide for them.”



Eating Well

A well-balanced, nutritional diet supports you in treatment and recovery.

Why good nutrition is so important

Cancer itself and the ensuing treatment places extra demands on your body, so it's important to understand how nutrition and exercise can help during treatment, recovery and beyond.

Eating a well-balanced diet can help you to maintain a healthy weight, sustain muscle strength and boost your energy levels – all of

which contribute to your quality of life. Good nutrition can also assist with enhancing your mental health, managing the side effects of treatment, wound healing and rebuilding damaged tissues (especially after surgery, radiotherapy, chemotherapy or other treatment), improving your body's immune system and reducing the risk of cancer recurring.

Tips for Eating Well During Cancer Treatment

Eating Well during treatment looks different for everybody, so an individualised approach is vital. It's important to understand that different treatments will have different side effects, and everyone responds differently.

You may be affected by loss of appetite, nausea, taste changes or bowel changes, such as diarrhoea or constipation. There are a range of tips to manage these symptoms here. Taking care of your oral health, both during and after treatment, is also important.



Tips for Eating Well After Cancer Treatment

It's important that you try to maintain your weight, which will assist your recovery. Consult with your treatment team to get up to date and evidence-based information and to identify ways to assist you in your recovery. The following are recommended suggestions that may assist you.

- Eat a variety of foods from the five food groups - website eatforhealth.gov.au
- Fluids are vital – ensure you drink plenty of water
- Limit your alcohol intake and consumption of saturated fats
- Include some physical activity to rebuild your muscle mass and recover from the side effects of your treatment.



Tips for Eating Well in Recovery

Once you recover from any side effects of treatment, it's important to continue your healthy eating plan

- Focus on maintaining healthy body weight while being physically active to lower the risk of cancer recurring
- Consult your doctor for regular check ups.



Exercise

There are many benefits to physical activity and exercise.

Exercise is highly beneficial to our health and wellbeing and is regarded as one of the best medicines for our body and our longevity.

Research shows exercise can reduce the risk of some cancers and help prevent some types of cancer from recurring. Exercise is often included in cancer care to help counteract the adverse effects of cancer treatment.

A recent study of melanoma patients revealed:

- 56% of melanoma patients are physically active
- 77% nominating walking as their preferred activity
- 64% of patients reported immunotherapy affected their capacity to exercise
- Patients described a range of physical and emotional benefits
- Exercise is extremely important for fatigue reduction

Physical activity can help you to increase muscle strength, boost energy levels, improve our balance and mobility, relieve stress, enhance sleep and decrease anxiety, depression and fatigue.

Exercise recommendations for cancer patients

During treatment*

Strength training & Aerobic activity –



90 mins per week, comprising **3 x 30-minute sessions** of moderate intensity aerobic exercise.

After treatment*

Strength training & Aerobic activity –

aiming to build to standard exercise guidelines of **150-300 minutes** per week, with **2 sessions** of structured strength training per week.

Remember, more exercise equals greater benefits for you and your body.

*As individually tolerated





Tips to increase physical activity

- Always check with your treating medical team before commencing physical activity or an exercise program
- Ask a friend to walk with you or join a walking group
- Wherever possible, skip the lift or escalator and take the stairs instead
- Try getting off the train or bus a stop early or park your car further from your destination, then walk to your destination
- Activities around the home, such as vacuuming, gardening and lawn mowing are great physical activities with the added incentive of a positive end result
- If you need to sit behind a screen for long periods, stand up every half hour
- Try a new activity – join a yoga, stretch, dance, Pilates or tai chi class – or join your local gym
- Play with your children or grandchildren, hit or kick a ball around the yard or park.

Steps to getting started

1. Discuss your plans with your GP/doctor or those involved in your care plan
2. Consult an exercise physiologist via your GP, they will develop a plan to suite you and provide any additional support you may require
3. Make an exercise plan, including a commitment to the start date.



Financial Wellbeing

Planning and preparation can save you worrying about finances.

Your financial wellbeing is vital, during your melanoma journey and beyond. Finances work in collaboration with your medical and emotional support networks. It's important to consider financial implications up front, rather than waiting until a situation becomes extreme. The goal is to be able to meet short and long-term cash flow needs.

Budget basics

Your plans may need to be recalibrated. The first thing to do is to create a monthly budget – boring but necessary. The best time to sort your finances is right now. Free budget calculators are available online.

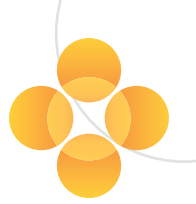
- Establish a timeframe – start with a monthly budget for say, a 6-month period
- Estimate your income
- Make a note of all your expenses – Mortgage/rent, food, car, etc.
- Calculate the difference
- Take stock of your assets and liabilities – owe vs. own

Understanding how much income you will have, and your expected expenses, is the basic framework to work with. Check whether your income matches your bills. If not, it's time to seek financial assistance.

Where to seek assistance

Your financial planner/advisor and accountant assist with your financial strategy now and into the future, using options suited to your individual situation, including managing debts, superannuation, insurance and estate planning. As industry professionals, they know all the potential assistance available and the eligibility criteria for each. They can provide strategic advice before you apply for any assistance. Your ability to receive payments varies depending on your own circumstances and those of your partner, if you have one.





The next steps:

Step 1

MyGov.org – If you haven't already set up a MyGov account, do it now. This will provide access to Centrelink, the ATO and Medicare.

Step 2

Centrelink can arrange a meeting with a financial information officer, which is free and independent.

Step 3

Centrelink may be able to provide:

Income support - Jobseeker, Sickness allowance, Disability Support Pension, Carer's payments and allowances.

Concessions and rebates - Health Care Cards, Care Benefit, PBS Safety Net, Medicare Safety Net, utilities concessions/ rebates and mobility allowance.

Step 4

You may also be entitled to other assistance from:

The Patient Assisted Transport Scheme (PATS) may be available for people in regional and rural areas who need to travel to a nearby town or distant city for treatment. This is provided by each State government.

Local community health services, volunteer resource centres and support groups, e.g. MPA.

Speak to your GP to find out which medications are subsidised through the PBS and to seek any further advice or tips they may be able to provide about claiming costs.

- Cancer Council Website – cancer.org.au or Helpline 13 11 20
- MyGov Website – centrelink.gov.au
- Australian Cancer Survivorship Centre Website – petermac.org

Routine Health Checks & Monitoring

Check-ups are vital for your health and your peace of mind.

Following a melanoma diagnosis and/or treatment, it is essential to follow up with regular health checks and monitoring as per your medical team's advice. It's also important to understand your melanoma risk.

Melanoma Statistics

- Australia has the highest incidence of melanoma in the world
- Melanoma is the most common cancer in Australians aged 20-39 years
- Melanoma affects over 16,000 Australians annually.

Skin Surveillance

Full skin examinations are vital

Process

A top-to-toe check, including examination of lymph nodes, melanoma scars and any lesions you are concerned about.



Who?

Your skin surveillance can be undertaken by a dermatologist or your GP.

Frequency

Depends on your individual risk factors, generally 3-6 monthly if you have a history of melanoma. Discuss this with your doctor.



The importance of self-examination

Process

Frequent self-examination is strongly advised. Choose a date, such as the 1st of each month to check your own skin.

Who?

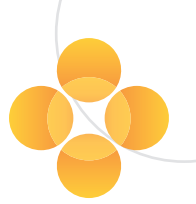
Ask your partner or a close friend to check anywhere you can't see yourself. Hairdressers are a great option for your scalp.

The ABCDE rule – Look for:

- **A**symmetry
- **B**order irregularity
- **C**olours – Does it have multiple colours?
- **D**iameter – Is it more than 5mm?
- **E**volution – Is it new or changing?

Remember, melanoma comes in all shapes, sizes and colours. If you're concerned, get it checked by a doctor.





Mindfulness & Relaxation

Anxiety is very common when you have been diagnosed with melanoma.

Your level of anxiety can depend on many factors such as:

- Your current mental state when receiving a diagnosis
- Anxiety and depression that runs in the family
- Your social circumstances

Even when you make it through the treatment, it is very common to experience fear of cancer recurrence (FCR). This is an acknowledged condition that is very common in people who have been diagnosed with melanoma.

There are many ways to deal with anxiety which we will cover below. But first, let's unpack what is happening in the body when you're feeling anxious or stressed.

Signs and Symptoms of Anxiety

There are many symptoms that you may feel if you are experiencing anxiety. Sometimes, you may not even be aware that what you are experiencing is an anxiety symptom. Here are just a few:

1. Physical Symptoms:

There are many physical symptoms that you might feel including a racing heart, shallow breathing, dizziness even panic attacks.

2. Brain Fog and Forgetfulness:

When you are experiencing high levels of stress your body releases the hormone cortisol. High cortisol levels can cause loss of memory.

3. Insomnia:

Nighttime can be hard for some people experiencing anxiety. Throughout the day you can stay distracted and busy, but when it's time to fall asleep you are forced to sit with your feelings, worries and busy thoughts.

4. Feeling Like You Can't Control Your Thoughts:

When you are feeling anxious it can be hard to control your thoughts. You might be having "worst-case scenario" thoughts and even be dwelling on things you have said or done.

5. Tired but Wired:

You may already be feeling fatigued from your treatment, however, you may also be feeling "wired" which is when you are exhausted, but you can't switch off your mind and body to relax or fall asleep.

6. Staying Too Busy:

You might feel like you're not able to stop. It might be work, cleaning or even doing too much for others. This is a way to distract yourself from feelings of panic and worry. The problem with this is that it keeps you in fight or flight mode and increases anxiety making it harder to relax or sleep.



supportive family or friends and yet still feel alone if they don't fully understand what you are going through.

But you never have to feel alone whilst you are going through this. Here are some steps to take to get proper support.

Tips for Managing Anxiety

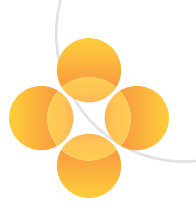
Depending on your level of anxiety, you may need medication to help you get through this difficult time. However, there are also many other things that can help you manage your anxiety as well:

- Meditation
- Mindfulness
- Yoga
- Self-care
- Start a Daily Gratitude Practice
- Get as Much Sleep as Possible
- Reduce Alcohol and Caffeine

Get the Right Support

Studies have shown that people who feel more connected to others have lower levels of anxiety and depression. You might even have

- Visit your local GP and get a referral to a psychologist. By going through your GP, you can ask for a GP Mental Health Plan and you may be eligible for up to 20 sessions per annum with a psychologist.
- If you feel like you aren't connecting with your psychologist or that you're not gaining any benefits from the sessions, don't give up on therapy. You just haven't found the right person to help you yet. Ask around for recommendations and go back to your GP to get another referral.
- Call us on 1300 88 44 50 to get more information on resources that are available to you or to be connected to our Melanoma Telehealth Nurse.
- Join our supportive Facebook Community and reach out for emotional support or to ask for advice.



Acknowledgements

Melanoma Patients Australia extends gratitude to the many people who have worked to develop this Melanoma Patient Guide.

Contributing Authors and Reviewers

- Brent Grace, MPA Co-Founder
- Professor Mark Smithers AM, Director, Upper GI/Soft Tissue Unit, Professor, Discipline of Surgery, The University of Queensland, Princess Alexandra Hospital, Brisbane
- Dr Melissa White M.B.B.S., BA (Hons)
- Turner Freeman Lawyers
- Sarah Lumchee, B. Pharm, Princess Alexandra Hospital
- Ms Bronwyn Smith, Gallipoli Medical Research Foundation, Clinical Trials Co-Ordinator
- Palliative Care Australia
- Carers Australia
- Jo Crotty, Danger Sun Overhead
- Jenny Fox, B. Nurse, RN, PHD Candidate, Grad Cert Palliative Care, Research Assistant QUT
- Dr Victoria Atkinson, Medical Oncologist Princess Alexandra Hospital and Greenslopes Private Hospital
- Dr Robyn Box, MPhy, PhD, Physiotherapist, QLD Lymphoedema and Breast Oncology Physiotherapy
- Glaxo Smith Kline Australia
- Australian Clinical Trials
- Consumers Health Forum of Australia
- Bristol Myers Squibb
- Professor Michael Kimlin, Foundation Professor in Cancer Prevention, Cancer Council Queensland
- Ms Karen van Gorp, MPA Director

Contributing Images, References and Graphics

- Aim at Melanoma
www.aimatmelanoma.org
- TopDog Advertising
www.topdogadvertising.com.au
- Glaxo Smith Kline Australia

Many Melanoma Patients Australia members have kindly given comments about their melanoma journey and these are included throughout this Patient Guide. For their privacy, we have only provided first names, however, MPA wishes to acknowledge their contribution and bravery in sharing their stories.



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