



Melanoma Patients Australia

"A Community of Support in a Time of Need"

A guide to Understanding Melanoma

a starting point for people in
their journey with melanoma

Foreward

**“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.

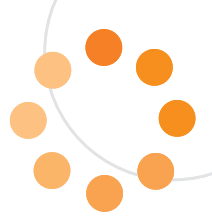
This guide offers introductory information to melanoma patients as well as their carers, family and friends. Throughout this booklet you will find references to external resources and organisations that can provide you with more in depth information and specific advice regarding your personal situation.

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

To reduce the impact of melanoma on all Australians.

Mission

Raise awareness of melanoma, provide information and support for those affected by melanoma and represent the interests of all Australian melanoma patients.

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.

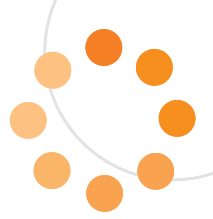
MPA Patient Programs and Services - How we can help you?

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:

- > Hosting public melanoma forums in regional communities and metropolitan cities.
- > Offering a community of friendship and peer to peer support to melanoma patients, their family, carers and friends, through face to face support groups, online resources (website www.melanomapatients.org.au), social media and telephone link ups (telephone 1300 88 44 50).
- > 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.

All of the services offered by MPA to patients are offered at no cost and are freely accessible by melanoma patients, their carers, family and friends. 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: Free counselling with a qualified counsellor is available **1300 88 44 50** (cost of a local call anywhere in Australia).
- Support Group Meetings: Meet other members, listen to speaker presentation from various organisations, attend social events.
- Facebook support: 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, of which 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?

Melanoma is an uncontrolled abnormal growth of the melanocyte cells.

Primary Melanoma

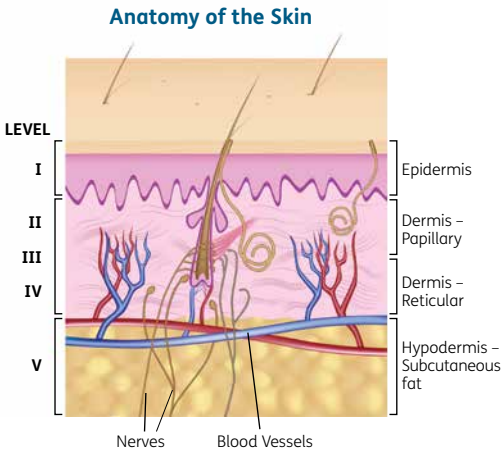
Primary melanoma refers to the first instance of melanoma occurring in the patient. The primary melanoma is generally occurs in the epidermis but can be present in some patients in the eyes, mouth, ears and other parts of the body containing melanocyte cells.

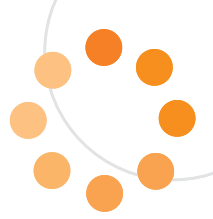
Secondary Melanoma

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

Melanoma of Unknown Primary (MUP)

In some instances, metastatic melanoma can be diagnosed in a patient without a primary melanoma lesion ever being detected. This is known to occur in a small percentage of melanoma patients.





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. You may require a referral from your general practitioner.

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 a non-invasive form of examination in which a hand held tool called a **dermatoscope** is used to assess pigmented skin blemishes and moles. 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 appears suspicious under the dermatoscope, a **biopsy** is taken for further evaluation.

Biopsy is an invasive form of examination in which a sample of tissue is taken from the suspicious skin lesion and examined under a microscope by a pathologist to determine its abnormal cellular properties. A representative slice of the skin lesion can be taken (an incisional biopsy) in order to look at the cells. An excisional biopsy is when the whole skin lesion is removed for further diagnosis. For pigmented lesion or when there is a suspicion of a diagnosis of **melanoma** usually an

excisional biopsy is performed because the depth of the tumour is essential for staging the disease and it is only by taking the entire lesion that the depth can be accurately measured. Sometimes other forms of biopsy such as a punch biopsy or a shave biopsy are performed to take a sample when considered appropriate by the doctor. 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 long **radial** growth phase 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 a lesion with irregular borders and uneven pigmentation.
- **Nodular melanoma:** This is the most aggressive form of melanoma as it undergoes no radial growth phase and instead enters a **vertical growth** phase from the outset. Nodular melanomas are typically characterised by 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 cells found in the lowest part of the epidermis called **melanocytes**. If the melanoma is contained in the epidermis

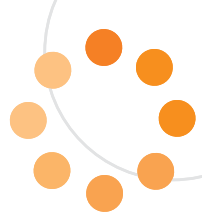
when removed it is called “in situ” or “level I”. It should be cured at this stage.

If malignant cells make it to the capillaries under the epidermis they can be washed into the blood and the abnormal cells become blood-borne. Given time and unchecked, malignant cells are able to 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 7 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 8-9 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.

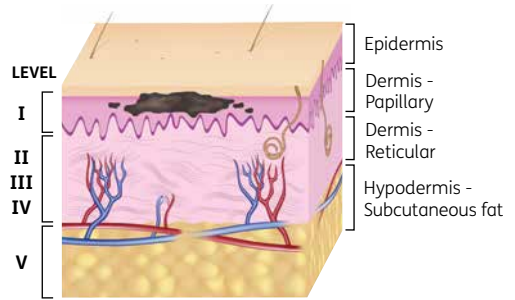
It is important to understand the difference between Staging and Levels of Melanoma. To avoid confusion between you and your treating doctors, you can ask your doctor to explain to you what Level of Melanoma you may have as well as what Stage of Melanoma you have been diagnosed with. For example, a Level 4 (or Level IV) melanoma is not the same as a Stage IV melanoma patient. The medical profession has started 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 7 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

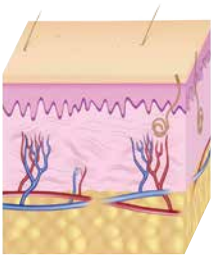
Cutaneous Melanoma (melanoma originating in the skin) grows and spreads in two phases, called the radial and vertical growth phases. During the **radial growth phase** melanoma grows horizontally across the surface of the skin. The risk of spread from the melanoma at this stage is low. The **vertical 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

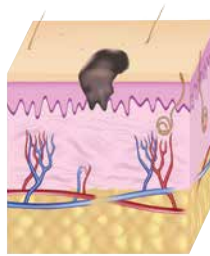


In Situ Melanoma

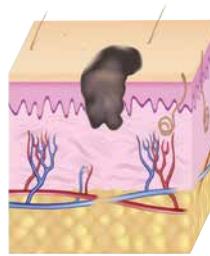
The Vertical Growth Phases of Melanoma



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

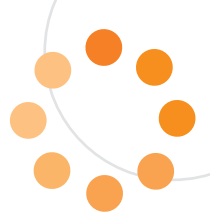
Breslow Depth

It measures in millimetres how thick the actual primary tumour is. Breslow depth is measured starting at the outer layer of the epidermis downward to the deepest extension of the melanoma. It has replaced Clark Level as a more accurate measurement of tumour depth, and is more predictive of prognosis.

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

When you have been diagnosed with melanoma, the next step is that you will be advised what “stage” of melanoma you have. A diagnosis of melanoma is **staged** by a pathologist giving an assessment of the depth the melanoma invades into the skin to determine how advanced the melanoma is.

The prognosis of melanoma and the treatment options available to patients very much depend on the stage at which the cancer is diagnosed. The four stages of melanoma are determined by reviewing different features.

Tumour Depth: How deeply the tumour has penetrated the skin. This is measured by the pathologist 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.

Mitotic Count: This refers to the number of cancer cells that are in the process of dividing when tissue is examined microscopically. Higher mitotic rates infer more rapid activity and a faster division of cells indicating a more aggressive melanoma type. This assessment is most relevant when trying to assess the activity of the thin melanomas (<1mm).

Number of metastatic lymph nodes involved: The greater the number of lymph nodes containing melanoma, the less favourable the prognosis. A sentinel node biopsy is a technique sometimes used to determine whether metastases to lymph nodes has taken place. It involves the injection of a radioactive blue tracer dye around the site of the primary lesion and then examination of the first lymph node to take up the dye. A biopsy of the involved lymph node is taken and examined by a histopathologist to determine if the node tests positive for melanoma.

Site of distant metastasis: Melanoma that has spread to other areas of the skin only has a relatively better prognosis than melanoma that has spread to any other site in the body.

Medikidz: Advanced Melanoma is a valuable resource to help you understand what advanced melanoma is and how immunotherapy works to arm the body’s natural immune system to fight melanoma. The booklet is presented as a comic style to enable the medical information to be simplified and accessible to all ages and literacy levels.

To order your free copy of Medikidz: Advanced Melanoma contact the MPA head office today on 1300 88 44 50 or email us at info@melanomapatients.org.au.



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

STAGE 0

In **Stage 0** melanoma, the malignant tumour is still 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. 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. A Stage I melanoma may or may not have ulceration. There is no evidence the cancer has spread to lymph nodes or distant sites (metastasis). There are two subclasses of Stage I Melanoma: *1A, 1B*, referring to whether ulceration is not present (*A*) or present (*B*).

STAGE II

Stage II melanoma is defined by tumour thickness, and ulceration. There is no evidence the cancer has spread to the lymph nodes or distant sites (metastasis). There are three subclasses of Stage II: *IIA, IIB, IIC*.

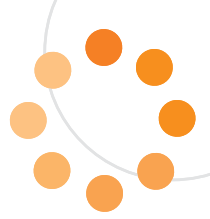
STAGE III

Stage III melanoma is defined by the presence of lymph node involvement along with ulceration in the skin melanoma. For Stage III melanoma, the depth of the melanoma no longer matters. There is no evidence the cancer has spread to distant sites (metastasis). There are three subclasses of Stage III Melanoma: *IIIA, IIIB, IIIC*. The subclasses relate to the size and number of glands that contain the melanoma cells.

STAGE IV

Stage IV melanoma occurs 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

Surgery for a primary melanoma –Stages 0-I-II

For patients in stage 0, I or II, surgery is the main treatment. Surgery of a primary melanoma includes, but may not be limited to, the removal of the primary tumour with excision margins. **Excision margins** involve the removal of skin and flesh from around the primary tumour along with normal skin with the aim of catching adjacent high-risk cells that may be present in the skin around the melanoma.

The treatment of the primary lesion will also 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 may be required after the removal of the melanoma. After the surgery, a pathologist determines whether margins are clear by examining 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 such as the neck, arm pit (axilla) or groin. A **removal or block dissection** of lymph nodes in the region surrounding the node/s that tested positive for melanoma is undertaken. This is done because there is a risk that there may be other nodes involved with melanoma that cannot be seen or felt. Again, a pathologist helps to determine whether 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 can not have the melanoma taken out surgically because it is too extensive. For stage III melanoma post-operative radiotherapy is also considered in patients who are considered to be in a high risk group for the melanoma recurring in the operated region.

Biological Therapy

Biological therapies work with or enhance the immune system to fight cancer. Biological therapies include treatments such as interferons, interleukins, colony stimulating factors, monoclonal antibodies, gene therapies and cancer vaccines.

For the treatment of **Stage III melanoma**, a biological treatment using high dose Interferon Alpha 2b is sometimes considered. Interferons are types of cytokines which are produced by white blood cells. Interferons are produced naturally in the body and help regulate the intensity and duration of the immune response. This treatment has side effects and it is recommended that you speak to your doctor about any concerns you may have.

Chemotherapy

Systemic therapy implies that the whole body is being treated. This means that drugs or vaccines are being delivered either through the veins or by mouth.

While chemotherapy is a systemic treatment, it 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.

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 (ie over 10 weeks) through an intravenous infusion (ie a drip).

Yervoy is listed on the Pharmaceutical Benefits Scheme (PBS) for advanced melanoma.

Keytruda (pembrolizumab) 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.



Immunotherapy & Targeted Treatments for Advanced Melanoma *continued*

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.

Keytruda is administered intravenously every 3 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 BRAF wild-type advanced melanoma and as a 2nd line treatment of BRAF mutation positive advanced melanoma.

Opdivo® (nivolumab or “nivo”) 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 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 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 first line treatment of BRAF wild-type advanced melanoma and as a 2nd line treatment of BRAF mutation positive advanced melanoma.

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; 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.

Immunotherapy & Targeted Treatments for Advanced Melanoma *continued*

The combination is **Therapeutic Goods Administration (TGA)** approved only for patients with **Stage IV (metastatic)** melanoma defined as Stage M1C or elevated LDH:

- Stage M1c describes the situation where a patient's melanoma has spread beyond the lungs to other organs or sites around the body.
- Elevated LDH (lactic dehydrogenase) is an enzyme found in blood at increased levels when healthy tissue is damaged. LDH levels are considered when staging advanced melanoma.

When used in combination:

- Opdivo and Yervoy are administered together for the first four treatments, every 3 weeks (ie four treatments over 10 weeks).
- Opdivo is then administered on its own every 2 weeks.
- Treatment is stopped if the cancer progresses or there are unacceptable side effects.

The combination of Opdivo and Yervoy is approved by the Therapeutic Goods Administration (TGA) in Australia but not reimbursed on the Pharmaceutical Benefits Scheme (PBS).

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 tumors, and releases tumor-derived antigens, which along with GM-CSF, may promote an anti-tumor immune response. However, the exact mechanism of action is unknown.

Imlygic is injected every 2 weeks for a period of 6 months at which point treatment ceases if there has been no response. Alternatively

treatment continues until the tumours are no longer present.

Imlygic is a live virus patients and therefore proper handling and wound dressing is important. It presents a treatment option for a subset of patients that have comorbidities, are elderly and/or frail or that have a poor IV profile as it is well tolerated with few side effects.

This treatment is not available on the PBS at this time.

Interferon (Interferon-alfa2b, IFN, Intron A) is a naturally occurring protein that is part of the body's immune system. Interferon used to treat melanoma is produced in a laboratory using genetic engineering.

Interferons are cytokines, which are chemicals produced by white blood cells in response to a virus, bacteria, or other foreign bodies. They attach to foreign cells and cause changes including slowing down the rate of cell division and reducing the ability of a tumour cell to protect itself from the immune system.

Interferon is usually given intravenously over one month and then subcutaneously to complete a 1-year period and is sometimes considered for Stage III melanoma (after surgery and free of disease) to reduce the likelihood of melanoma returning.

Side effects include severe flu like symptoms and fatigue.

The treatment is rarely used 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 can be important in determining your treatment pathway. The genetic tests are performed on a tumour sample from a biopsy.



Immunotherapy & Targeted Treatments for Advanced Melanoma *continued*

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.

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 50% of melanomas have BRAFV600 mutations. Targeted therapies 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.

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

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

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

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

Zelboraf and Cotellic can cause side effects. The most common side effects include sunburn or sun sensitivity, Cutaneous Squamous Cell Carcinoma (lesions) skin rash, blistering, swelling of the face, hands, or soles of the feet, joint discomfort and eye problems.

The combination of Zelboraf and Cotellic is not listed on the PBS.



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:

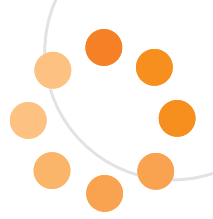
Treatment trials: These involve trials of experimental treatments, drugs or new approaches to surgery or radiation therapy.

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 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.

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 for 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.

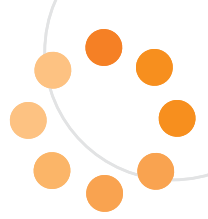
CANCER TRIALS AUSTRALIA

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 eyewear. 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

Lymphoedema is a swelling that may occur after treatment for melanoma as lymph fluid builds up when flow is reduced from a part of the body. Lymph fluid drains from the tissue spaces through vessels that pass through the lymph nodes and eventually drains back into the blood circulation. Lymph nodes are located in armpits, groins, abdomen, chest and neck to filter out harmful bacteria and assist in the body's response to infection. The movement of lymph fluid around the body is dependent upon changes in tissue pressure that occur with deep breathing, muscle contraction and movement.

The management of melanoma may require the surgical removal of lymph nodes or radiation to nodes affected. This results in an obstruction to the flow of lymph fluid flowing from the area of the body drained by the treated lymph nodes.

Lymphoedema may present at any stage after surgery or radiation with symptoms of ache, heaviness, tightness or swelling most commonly reported. It is usually a slow and gradual increase in swelling and symptoms in the limb and body part. For example, 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.

Not everyone will develop Lymphoedema but it is known that early detection and intervention can assist in minimising its impact. Things that may affect the risk of developing swelling could include infection, higher body mass index (being overweight or obese) or immobility (lack of use).

Lymphoedema is diagnosed by patient history and physical examination with measurements such as Bioimpedance (a method of measuring tissue fluids in the limb), circumferential (tape measure), perometry (imaging with computer calculation of limb volume) or indurometry (tissue texture/density).

Managing lymphoedema and depending upon the presentation includes:

- > massage (manual lymphatic drainage),
- > exercise,
- > skincare,
- > compression therapy (bandaging and/or compression garments),
- > low level laser therapy,
- > other electrical or vibratory stimulation.

Treatment may include a combination of these to achieve the best improvement for individuals.

Major components of lymphoedema treatment is self-management of the chronic condition, which should develop in partnership with a treating practitioner. Assist in reducing loads on a compromised lymphatic system includes:

- > maintain healthy weight range,
- > good skincare and avoid trauma or infection,
- > participate in regular physical activity seek health professional advice before starting a new activity,
- > monitor your limb for changes in size or symptoms periodically and seek advice if changes are observed.

For further information

AUSTRALIAN LYMPHOLOGY ASSOCIATION
www.lymphoedema.org.au/ALA/Lymphoedema/What_is_Lymphoedema/ALA/Lymphoedema/What_is_Lymphoedema.aspx

To find a treating practitioner

THE NATIONAL LYMPHOEDEMA PRACTITIONERS REGISTER OF THE AUSTRALIAN LYMPHOLOGY ASSOCIATION
www.lymphoedema.org.au/ALA/



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?

Low levels of the marker used to measure vitamin D status (25(OH)D) have been implicated in just about every possible health outcome, from cancer and cardiovascular disease through to aches and pains and even wrinkles. However, a number of organisations (such as the United States Institute of Medicine) and eminent scientists (Autier, 2014) have concluded that bone health is the only outcome where there is sufficient evidence that vitamin D is important. For all other outcomes the evidence is inconsistent.

2. Does suboptimal vitamin D status influence my risk of skin cancer?

It is extremely difficult to determine the effects of circulating 25(OH)D on skin cancer, as exposure to UV radiation induces both. To sort this out we really need large randomised trials of vitamin D supplementation. One such trial being carried out in Australia is the D-Health Trial (www.dhealth.qimrberghofer.edu.au). A previous trial that has published information about melanoma did not find any benefit of vitamin D supplementation on overall risk of melanoma, but in people with a previous history of nonmelanoma skin cancer there was some evidence that taking 400 IU of vitamin D per day reduced risk of melanoma (Tang 2011).

3. How much vitamin D (25(OH)D) should I have in my blood?

There is quite a lot of controversy about this issue. The Australian recommendations are that 50 nmol/L is sufficient, but that you should possibly aim for slightly higher than this at the end of summer to ensure levels are maintained through winter.

4. Doesn't Australia have an epidemic of vitamin D deficiency?

Not really. The most recent National Health Survey shows that only a quarter of Australians have a 25(OH)D concentration of less than 50 nmol/L. Most of these have a level between 30 and 50 nmol/L which is considered to be only mildly deficient and the health implications of this are unclear. Only 7% of the population has vitamin D deficiency at a level that we are sure increases risk of poor bone health. The risk of vitamin D deficiency is much higher in people born in Asia or Africa than in those born in Australia, and the proportion deficient is highest in people aged 18 to 34 years (www.abs.gov.au/ausstats/abs@.nsf/Lookup/4364.0.55.006 Chapter 2002011-12).

5. Should I have a vitamin D test?

The Australian government currently spends approximately \$150 Million each year on vitamin D testing. This is almost certainly inappropriate for the following reasons: Firstly, given the lack of consensus about how much 25(OH)D is needed in the blood, it is difficult to know how to advise patients. Secondly, the test is notoriously unreliable meaning that your results may not reflect your true vitamin D level. Finally, there is insufficient evidence that treating people with vitamin D deficiency that has been detected through screening, and who have no other markers of deficiency such as high levels of parathyroid hormone or soft bones, is of any benefit. In other words, doctors should only order vitamin D tests if there are other clinical factors indicating that vitamin D might be low.



6. Should I take a supplement?

There is limited evidence that taking a supplement is of any benefit. However, the Australian recommendations are that if you are under 70 years old and you receive no sun exposure at all you should take 400 IU of supplementary vitamin D each day. If you are over 70 years old and receive no sun exposure, you should take 600 IU daily.

7. How much sun is enough to make vitamin D?

This is a difficult question to answer when we don't even know how much vitamin D we even need in our blood streams! The amount of

sun exposure required will vary by the time of year, skin type, age, body mass index and a number of other factors. Importantly, if you expose more skin you can stay outside for a shorter period of time. This reduces the amount of sun exposure to any one area of your skin. You would be better exposing your abdomen and upper legs for a few minutes than your face and hands for half an hour. The Australian recommendations are that when the ultraviolet index is less than 3, which is the case for most of Southern Australian states in winter, you do not need to protect yourself from the sun.

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.

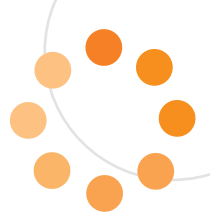
To ensure that the information you receive is correct and to assist you with pursuing a claim for your entitlements you should seek legal advice.

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 Australia 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.”



Acknowledgements

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

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- Dr Robyn Box, MPhty, PhD, Physiotherapist, QLD Lymphoedema and Breast Oncology Physiotherapy
- Glaxo Smith Kline Australia
- Australian Clinical Trials
- Consumers Health Forum of Australia
- Bristol Myers Squibb

Contributing Images, References and Graphics

- Aim at Melanoma
www.aimatmelanoma.org

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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