



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.

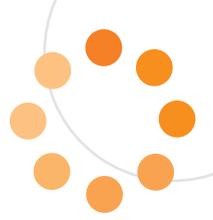
Wherever you are on your melanoma journey, Melanoma Patients Australia is here to support you. Being diagnosed with melanoma can be an isolating, confusing and frightening experience and hopefully this booklet can clarify some of the questions you may have.

John Stubbings



President
Melanoma Patients Australia

Melanoma Patients Australia: *"A Community of Support in a Time of need"*



What is Melanoma Patients Australia?

Melanoma Patients Australia was established in 2006 by two young men, Daniel Belcher and Brent Grace, whose personal journey with melanoma inspired them to create an organisation to provide melanoma patients with a source of information, support, advocacy and awareness.

Melanoma Patients Australia was officially launched on 6 July 2006 by then Governor of Queensland, Her Excellency Quentin Bryce AC, now Governor-General of Australia.

Melanoma Patients Australia continues to grow in strength and numbers and is now one of the largest melanoma patient advocacy groups in Australia. 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.

Melanoma Patients Australia proudly hosts free regional public melanoma forums; offers a community of friendship and support to melanoma patients and friends through face to face support groups and online resources;

advocates on behalf of patients to all levels of government, as well as relevant service organisations, researchers and corporations; and, supports research and clinical trials seeking to offer the best options for melanoma patients.

More recently, Melanoma Patients Australia has affiliated with Danger Sun Overhead who deliver worksite presentations across Australia on sun safety work practices, melanoma prevention and early detection. Danger Sun Overhead is an initiative of Jo Crotty whose husband, Rohan, passed away from melanoma at 43. Since this time, Jo has devoted herself to raising awareness of skin cancer and melanoma prevention and early diagnosis. To date, Danger Sun Overhead has spoken to over 10,000 workers and been instrumental in the early diagnosis of over 200 melanoma cases.

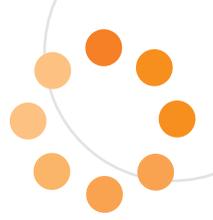
“I want to share our story because most melanoma can be prevented if people have access to education and awareness about skin cancer”

Jo Crotty, DSO founder and MPA member



“I believe that we all should be aware that melanoma can occur anywhere... not just on the outside skin.”

Heather, MPA member



Melanoma: A Medical Overview

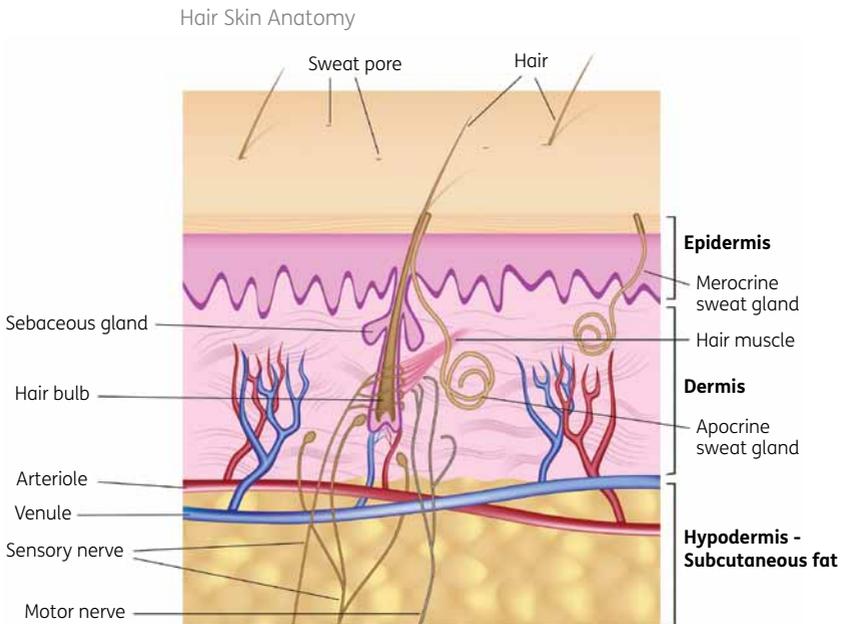
What is Melanoma

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. They relate to the depth in the dermis. Level V is the fat layer under 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. 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.

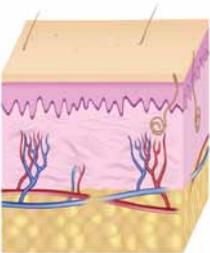
Biopsy is an invasive form of examination in which a sample of tissue is taken from the suspicious skin lesion and examined under a microscope by a pathologist to determine its abnormal cellular properties. A representative slice of the skin lesion can be taken (an

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.

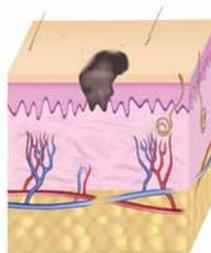
Growth phases of Melanoma

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 Vertical Growth Phases of Melanoma



Undamaged skin



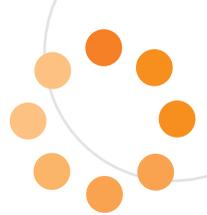
In early stages, melanoma spreads laterally across the top layer of the skin



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

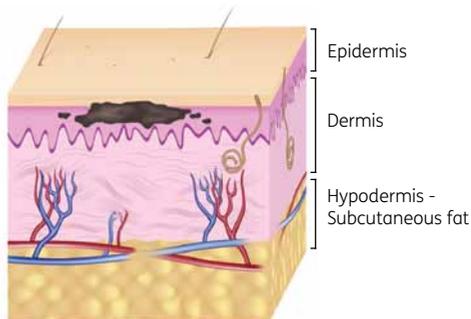


Types of Melanoma

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.

Radial Growth Phase



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.

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 then **staged** by the pathologist giving an assessment of the depth the melanoma invades into the skin to determine how limited or advanced this skin cancer 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.

Breslow Depth

It measures in millimetres how thick the actual primary tumor 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 tumor 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

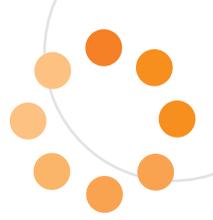
Tumour Ulceration: Ulceration of a skin tumour means that the epidermis (or top layer of the skin) that covers the melanoma is not intact. Ulceration may not be seen with the naked eye. Ulcerated melanomas pose a greater risk for metastatic progression.

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.

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.



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

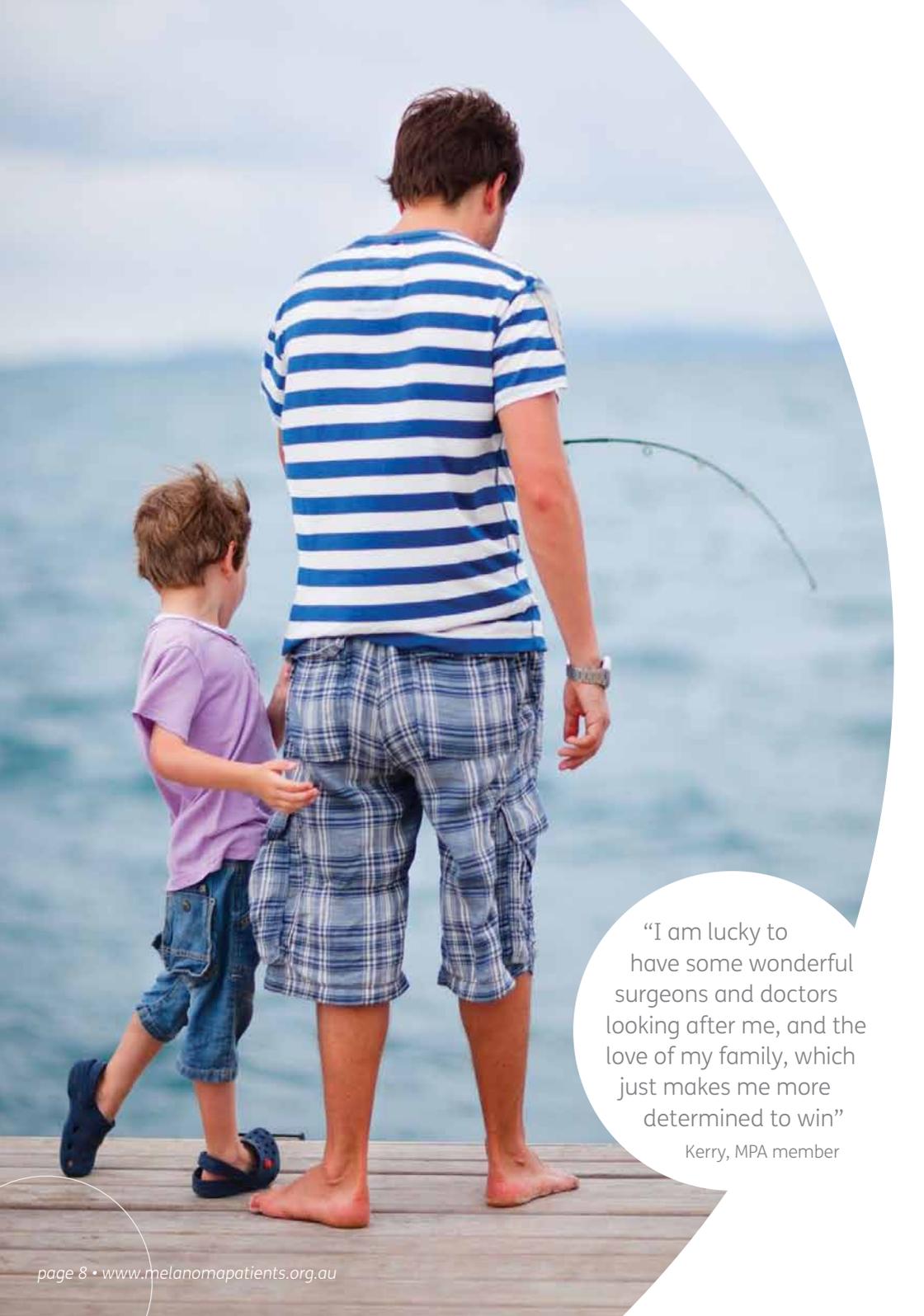
Stage II melanoma is defined by tumour thickness, and ulceration. There is no evidence the cancer has spread to the lymph nodes or distant sites (metastasis). There are three subclasses of Stage II: *IIA*, *IIB*, *IIC*.

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).



“I am lucky to have some wonderful surgeons and doctors looking after me, and the love of my family, which just makes me more determined to win”

Kerry, MPA member



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.

Some treatments available for patients in stage III

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.

Some Treatments available to patients in Stage IV

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.

Immune therapy

This is the area of the greatest research at this time. The focus is on making our own immune system recognise the abnormal cells or using drugs that stop the melanoma cells from dividing and growing. Recent trials have shown these approaches offer more hope than chemotherapy. However there is still a long way to go before we see long term benefits from these treatments.

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 NEW ZEALAND MELANOMA TRIAL 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.

CANCER TRIALS AUSTRALIA:

www.cancertrialsaustralia.com

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

AUSTRALIAN NEW ZEALAND CLINICAL TRIALS REGISTRY:

www.anzctr.org.au

The ANZCTR is an online register of clinical trials being undertaken in Australia, New Zealand and elsewhere. The ANZCTR includes trials from the full spectrum of therapeutic areas of pharmaceuticals, surgical procedures, preventative measures, lifestyle devices, treatment and rehabilitation strategies, and complementary therapies.

www.clinicaltrials.gov

An American based registry and results database of clinical trials conducted in the US and abroad, including melanoma specific trials.

International Organisations:

www.aimatmelanoma.org

Aim for Melanoma is an American organisation offering comprehensive medical information, facts and web videos.



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

"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

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.

For further information

www.melanomapatients.org.au

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LYMPHOEDEMA ASSOCIATION

The peak national body for the management of lymphoedema is The Australasian Lymphology Association (ALA) and their website provides useful information including how to find a therapist near you as well as the signs and symptoms of Lymphoedema.

www.lymphology.asn.au

BEYOND BLUE

www.beyondblue.org.au 1300 224 636

LIFELINE

131 114 (24 hours, Australia wide)

KNOW YOUR OWN SKIN

www.knowyourownskin.com.au

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



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

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CANCER COUNCIL WEBSITE

www.cancer.org.au

NATIONAL CENTRE FOR COMPLEMENTARY AND ALTERNATIVE MEDICINES

<http://nccam.nih.gov>

OFFICE OF DIETARY SUPPLEMENTS

<http://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 person, their family and carers. Palliative care is appropriate for people in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life. Care is delivered by a range of health professionals in a team approach, which allows them to address physical, emotional, spiritual, and social concerns that arise with advanced illness. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness — whatever the prognosis. Importantly, palliative care also provides care and supports for the person's loved ones and carers, both during treatment and also with grief and bereavement support.

Not every person diagnosed with melanoma will require palliative care and some patients receive treatment and palliative care at the same time. Many melanoma patients will survive following surgical and/or oncological treatment and will be able to continue living a vibrant life with the need for ongoing skin checks and regular consultation with medical specialists to monitor and manage the risk of melanoma recurrence.

Many health professionals are involved in delivering palliative care and work as part of a multidisciplinary team. A care team may include:

- > General practitioners
- > Specialist palliative care doctors and nurses
- > Specialist doctors, such as oncologists
- > Nurses
- > Allied health professionals – pharmacists, occupational therapists, physiotherapists
- > Social workers
- > Pastoral care workers
- > Grief and bereavement counsellors
- > Volunteers

If required, patients may seek to be cared for in their own home or choose to move into care with professional providers. Care is available through paid private providers, hospitals and hospices, as well as charitable organisations. Please consult with your treating specialists to find out what is the best option for you.

For further information

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PALLIATIVE CARE AUSTRALIA (PCA)

www.pallcare.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.

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
- > 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.

This section of the guide has been contributed by Turner Freeman Lawyers.

To receive legal advice you can contact Sean Ryan, Partner of Turner Freeman Lawyers directly on 1800 683 928.

Alternatively, you can visit www.melanomapatients.org.au to access details of the Law Society in your state.

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

Support Services

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

“This experience 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.”

Ellen, MPA member

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: **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.
- Online forum: Online support is available 24/7 for you to reach out for friendship, information and guidance. **www.melanomapatients.org.au**
- Regional Workshops and Forums: Melanoma Patients Australia regularly hosts training sessions for medical professionals (GPs, Nurses etc) to assist them in gaining a better understanding of melanoma from the patients perspective.
- Sun Safety Presentations: Schools and worksites (with Danger Sun Overhead).

Other Australian melanoma organisations

EMILY TAPP FOUNDATION
www.emilysfoundation.org.au

MELANOMA WA
www.melanomawa.org.au

MELANOMA AWARENESS FOUNDATION
www.melanomaawareness.org.au

MELANOMA INSTITUTE OF AUSTRALIA
www.melanoma.org.au

CANCER COUNCIL OF AUSTRALIA
www.cancer.org.au

CANTEEN
www.canteen.org.au

“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



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

Thomas, MPA member

Membership/Supporter Form

Melanoma Patients Australia Creating a Network of Support Across Australia

Melanoma Patients Australia provides information and support for those affected by melanoma. Our services are not only for melanoma patients, but also their family members, carers, colleagues and friends.

Name _____

Address _____

Town _____ Postcode _____ State _____

Phone _____ Mobile _____ Business _____

Email _____

DOB ____ / ____ / ____

Do you wish to receive electronic newsletters: Yes No

- I am a: Melanoma Patient - Stage 1 / 2 / 3 / 4 / unsure (please circle)
 Family member
 Carer
 Supporter

How did you find out about us?

- GP Skin clinic Hospital Website Word of Mouth Brochure Pharmacy
 Danger Sun Overhead presentation Workplace School Other

If you would like to support MPA, please tick your preference(s) below:

I would like to:

- Volunteer Offer my business services
 Make a Donation*:

- Please contact me to discuss donation options. Phone: _____
 I have included a chq/or money order made payable to Melanoma Patients Australia
 I made a direct deposit of \$ _____ to Melanoma Patients Australia
BSB: 124 001 Account: 208 298 92 under the name: _____
 Please charge my credit card: Visa MasterCard Diners Amex

Amount \$ _____

Card Number _____ / _____ / _____ / _____

Expiry date ____ / ____ / ____

Name on Card _____

Card holder signature _____



*Melanoma Patients Australia is a registered charity and deductible gift recipient. All donations \$2 and over are tax deductible and a receipt will be sent for your records.

Please remove this page once completed and return your completed form to: **Melanoma Patients Australia**
PO Box 1771, Toowong BC, Toowong Qld 4066

Acknowledgements

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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.

Contributing Images and Graphics

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www.aimatmelanoma.org
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Melanoma need not
be a lonely journey



mpa

Melanoma Patients Australia

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"A Community of Support in a Time of need"

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