



Melanoma: some useful facts

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Section 1 – Melanoma

Introduction

This booklet aims to provide you with information about melanoma – a type of skin cancer. The diagnosis of any potentially serious disease brings with it anxiety and uncertainty and some of this can be alleviated by knowing more about the problem. At the time of diagnosis it is difficult to take in all of the information that you are given and we hope this booklet helps to clarify and reinforce what you have been told. The first part concentrates on the diagnosis and initial treatment. This is followed by an explanation about your follow up appointments and self-examination between visits.

Organisations that can provide additional information and support are listed at the end of the booklet.

Your key worker

You will be given the contact details of a clinical nurse specialist (CNS). They will act as your key worker and is the person to contact with any questions you may have. These may relate to your diagnosis, your treatment and follow up or may be related to the anxiety and uncertainty that can be associated with a cancer diagnosis. They will also help to co-ordinate your care and may refer you on to other professionals if required.

You may worry that this nurse is also a Macmillan nurse. Macmillan nurses specialise in cancer, in your case skin cancer, and provide support and information to people with cancer, and their families, friends and carers, from the point of diagnosis onwards.

Keep hold of their number as they are here to help you not only in the next few weeks but also should you have any concerns in the months and years ahead.

Help with prescription costs

All cancer patients undergoing treatment for cancer, the effects of cancer or the effects of cancer treatment can apply for exemption certificates from their GP. This provides you with free prescriptions for 5 years.

Please complete application form, FP92A, which should be available from your GP surgery.

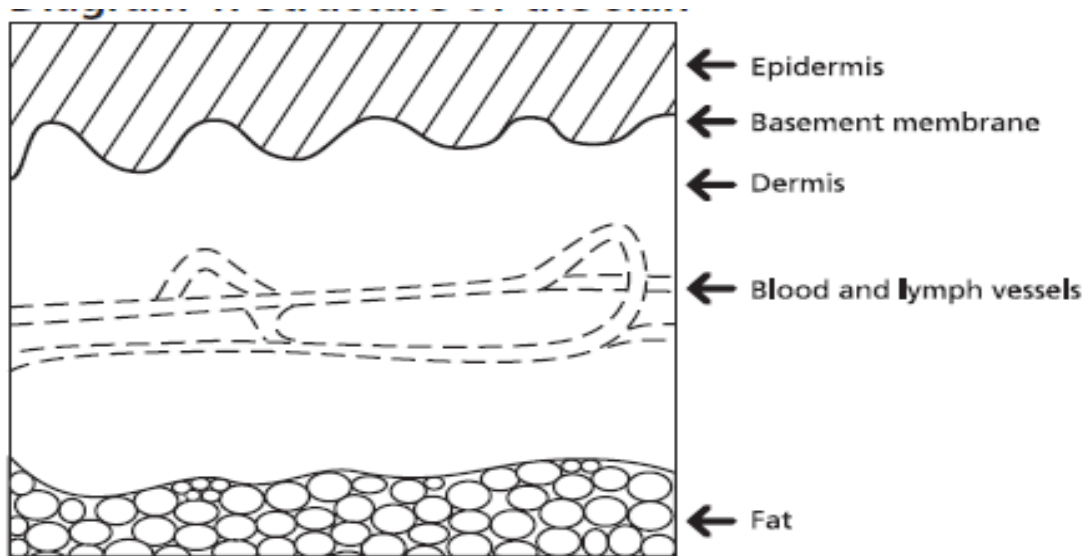
What is melanoma?

Melanoma is a type of cancer which usually starts in the skin. It is a cancer that grows from melanocytes – the skin cells which produce the protective pigment called melanin. Since most melanocytes are found in the skin, this is the commonest site for melanoma. Many, but not all, melanomas grow from moles.

Understanding the structure of the skin helps to show how melanoma develops.

The skin consists of a thin protective outer layer called the epidermis, and a thicker inner layer, the dermis. Each layer is made of individual “building blocks” called cells, and the two layers are separated by a boundary – the basement membrane.

Diagram 1: Structure of the skin



In the outer layer, the epidermis, are the melanocytes which make the pigment which causes our skin to look brown. This pigment is called melanin, and protects the skin from sunburn.

The second, inner layer, the dermis, contains blood and lymphatic vessels, which together form the 'plumbing' system in the skin. The skin is constantly wearing out and replacing itself by making new cells. Sometimes things go wrong and the cells replace themselves too quickly. This results in a tumour, which is simply a cluster of abnormal cells. Tumours can be benign or malignant.

Benign tumours are usually quite small, they do not grow into the surrounding tissues, and they do not spread elsewhere in the body. Benign tumours are not cancer.

Malignant tumours can invade and destroy surrounding tissues and may spread or 'metastasise' to other parts of the body. Malignant tumours are cancer.

It is important to remember that cancer is not one disease; it is a group of many diseases. Each type of cancer differs from the others in many ways and the diagnosis, treatment and follow up varies between types of cancer.

Cause of melanoma

The precise cause of melanoma is not fully understood. However there is evidence to suggest that ultraviolet radiation from the sun may damage the skin and cause melanoma. In general the risk is greatest in those with white skin, especially those who burn easily and tan poorly. It is also greater in those with a large number of moles. Melanoma can be inherited but this is very uncommon.

Types of melanoma

Melanomas in the skin occur in two main forms:

- A. in-situ melanoma
- B. invasive melanoma

A. In-situ melanoma

This type accounts for about 10% of the melanomas that we see in our clinic. The most important point about in-situ melanoma is that it is harmless. The cancer cells are confined to the top layer

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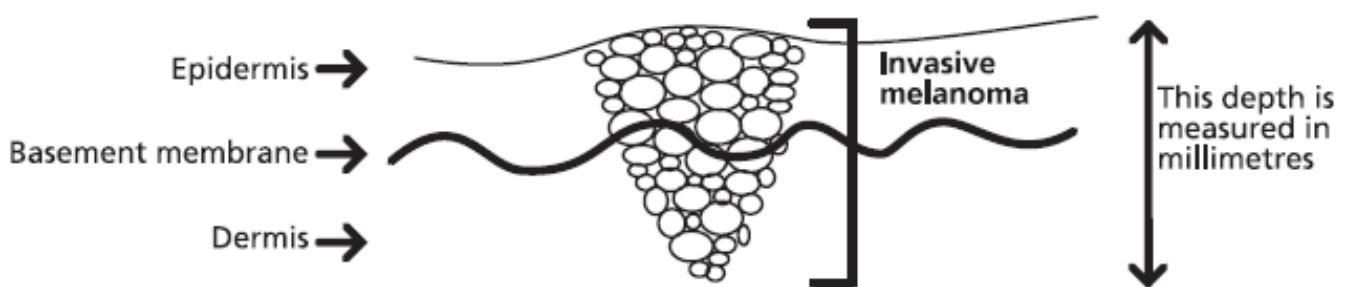
of the skin, the epidermis. They are separated from the blood vessels and lymphatic vessels by the basement membrane, as previously shown in diagram 1. However, if untreated in-situ melanoma can continue to grow and break through the membrane and could then potentially spread. For this reason it is important that they are treated.

B. Invasive melanoma

Invasive melanomas are not confined to the top layer of the skin. They grow through the basement membrane into the deeper layer, the dermis. Here, blood and lymph vessels are present which can provide a route for cancer cells to spread around the body. The further down a melanoma has grown into the skin, the greater the chance of the cancer cells getting inside a blood or lymph vessel, and being carried away from the skin to another part of the body. Invasive melanoma is therefore more serious than in-situ melanoma, because the cancer has the potential to spread.

The single most important point about your melanoma is therefore the depth to which it has invaded into the skin, the greater the depth or thickness, the greater the risk of spreading. This measurement is made very carefully on each melanoma that we remove. The measurement is made by an expert pathologist using a microscope. It is measured in millimetres and is referred to as the Breslow thickness (diagram 2).

Diagram 2: Breslow thickness



It is important to realise that for most melanomas the chance of spreading is small, because most melanomas remain close to the surface.

The thinner the melanoma, the smaller the chance of it having spread before it was removed, and the greater the chance of cure. If you want to know more about this in detail please ask your Consultant or CNS. However, it is important to remember that about 80% of all patients with melanoma are cured.

Section 2 – Treatment

The treatment of melanoma should be provided by a team who have specialist knowledge and experience in its management.

Diagnosis and treatment:

Melanoma is usually managed in two stages:

- A. Biopsy; and then
- B. Further surgery

A. Biopsy

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Where possible the entire mole or lesion is removed under local anaesthetic, with a margin of normal skin so that it is completely removed. The specimen is sent to the pathology department where it is examined carefully. If it is a melanoma, its thickness, along with some other features are looked at. This helps us to decide the most appropriate treatment for you.

B. Further surgery

Surgery is currently the only treatment which can cure melanoma. Radiotherapy, chemotherapy or other drug treatments are not used to treat primary melanoma as they are not as effective as surgery for this type of cancer. They are sometimes used if the melanoma recurs.

Using the information from the pathology report a further piece of apparently normal skin will be removed from around the original site. The difference from your biopsy is that the piece of skin is larger, but also deeper. The tissue that is removed is sent to the pathology lab to check for any further melanoma cells. This is necessary because cancer cells may be present around or underneath the melanoma even though the skin looks normal. The entire thickness of the skin is removed down to the muscle. Further surgery minimises the risk of leaving behind any melanoma cells in the surrounding skin. The amount of skin removed depends on the thickness of the melanoma. Table 1 illustrate this.

The surgery is often carried out using a local anaesthetic but it may sometimes be necessary to carry out this surgery under a general anaesthetic. Many patients will go home the same day whilst others will require a longer stay. Your key worker will be able to discuss this with you.

Table 1: Margin of skin taken in relation to Breslow thickness

Breslow thickness	Total margin of skin taken
In-situ	0.5mm
Up to 1mm	1cm
Over 1mm	2-3cm

Risks and benefits

As with any surgery there is a risk of bleeding and infection, you may experience some pain and you will be left with a scar. If there are any other risks relating to your surgery the surgeon will discuss this with you on the day of treatment.

The benefit of this treatment is that it reduces the risk of the melanoma recurring in the surrounding skin.

After surgery

After your operation you will be given information about any stitches that need to be removed, any dressing changes that are needed and be informed when you will next be seen in the outpatient clinic. Again this time varies from person to person and may be the following day or could be several weeks later.

The outpatient visit is also another opportunity for you to ask any questions about the diagnosis, treatment and follow up plan of care and to discuss how you are coping. You may find it helpful to bring a relative or friend with you, who can listen to what is being said.

Additional or 'adjuvant' treatment?

Many people ask whether there is any additional or 'adjuvant' treatment that may be helpful to prevent the melanoma from coming back. There are several points which are worth considering.

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Firstly, you do not need chemotherapy or radiotherapy for primary melanoma – these are not treatments which are used at this stage of the disease.

At present there is no proven adjuvant treatment for patients with primary melanoma. In general adjuvant treatment is not available outside clinical trials and these are designed to test new treatments. If there are any clinical trials that you may be eligible for you will be given information about these, but if it is not mentioned please feel free to ask a member of staff.

Sentinel lymph node biopsy (SLNB)

When melanomas spread they often do so via the lymph vessels to the lymph glands. For instance a melanoma on the leg would be expected to spread to the lymph glands in the groin and a melanoma on the arm would spread to the glands in the armpit. The first lymph gland to be affected is called the sentinel lymph node. It can be identified and removed to test whether the melanoma has spread. It enables us to find out if there has been any spread to the lymph nodes at the time of diagnosis and gives us a more accurate way to stage your disease. It is not an additional form of treatment. However, if the test does show further melanoma the team would discuss referring you to an Oncologist to consider whether any additional treatment would be beneficial.

The risk of lymph node involvement varies dependent on the thickness of your melanoma therefore this test may not be relevant for all patients with melanoma. If it is appropriate the team will discuss this test with you in more detail and give you more information so you can decide if you want to have the test.

Section 3 – Follow up Follow up

You will need to return to the outpatient clinic for a check up at regular intervals. The frequency of this varies from person to person and we will explain to you how often this will need to be. It may only be for several months or may be many years. If you have been referred to us from another hospital, your long term follow up treatment will most likely be back there once your treatment is completed.

What will happen at the clinic?

At the clinic you will be examined thoroughly and be given the opportunity to discuss any concerns. This appointment may be with a Doctor or a Specialist Nurse. You will be shown how you should be checking yourself between your appointments. If there is any sign of recurrence further investigations may be required before treatment.

The treatment for recurrence varies depending on where it is in relation to the original melanoma.

Recurrence within the scar or surrounding skin:

If the recurrence is around the scar, or within the skin between the scar and the lymph nodes, it will often be removed under local anaesthetic. This is similar to the original operation used to treat the melanoma, and involves removing the lump together with a small margin of normal tissue to ensure complete removal.

Enlarged lymph gland

If you do have an enlarged lymph node, a small sample of tissue may be taken through a thin needle whilst you are in clinic. Sometimes this small sample does not tell us whether there are cancer cells present or not so we may arrange an ultrasound scan with a further needle biopsy or may want to remove the whole lymph node to confirm there is melanoma present before we can plan your treatment.

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If the result shows melanoma cells, you will probably need to have an operation to remove all of the lymph nodes in that particular area. This is a major operation requiring a hospital stay of several days. If it is required we will explain it in detail and it will be carried out by a plastic surgeon who is experienced in this technique. We are likely to need to arrange additional investigations before this operation.

Risk of recurrence

The risk of the melanoma first recurring either in the scar, in the skin around the scar, the regional lymph nodes or elsewhere, is greatest in the first 4-5 years after diagnosis. Between 5 and 10 years, risk is significantly less; first recurrence more than 10 years after diagnosis is rare but not unknown. Consequently we would advise that you self examine every couple of weeks for at least 10 years and although the risk after this is very small it is sensible to continue.

Self examination

Although the chance that the melanoma will return is small for many patients, learning how to examine yourself for any sign of the melanoma coming back is probably the single most important thing you can do to help. Recurrence may still be curable if detected early so we will explain how you should be doing this, what you are looking for and how often you should do it. It is often helpful to bring a friend or relative with you to clinic to help you with this or simply to observe the process and encourage you once you are doing it yourself. Remember that checking the skin around a melanoma on the back may be difficult or impossible to do yourself and you may need some help. If you are not shown how to do this, or feel unsure whether you are doing it correctly, please ask for advice.

What do I need to look for?

When melanomas recur, they usually do so by appearing as lumps beneath the skin, often around where the melanoma was growing, or further up the limb, or as lumps in the lymph nodes. This means that they don't look like the original melanoma.

The lump will probably seem the same colour as the surrounding skin. It will however feel different from the surrounding skin; it often feels like a small, dried pea or a marble-sized, hard, smooth, round nodule. The lymph nodes are a common site for recurrence, probably because they are all linked to the lymph vessels which form part of the 'plumbing' of the skin.

After your surgery, once your wound is healed, we will show you how to check yourself and also provide you with some written information to help you with this.

What should I do if I think I may have a recurrence?

You should contact your key worker or the clinical nurse specialist team (**0121 371 6777**). We will probably arrange for you to be seen in an outpatient clinic within the next two weeks for assessment. If you contact other staff they may be unsure what to do and this may result in a delayed appointment. Please don't feel that you may be contacting unnecessarily or causing us extra work: we would much rather see you and reassure you than have you worry and risk delaying treatment.

However, if your concern relates to a new or changed mole elsewhere on your body, or your concern sounds like it may have a different cause, we may ask you to see your GP in the first instance.

Future sun exposure

Exposure of the skin to sunlight is clearly one of the causes of melanoma. Although your risk of developing a second, new primary melanoma is very small, reducing sun exposure may help. Simple changes, which you may wish to make, include:

- Do not allow yourself to burn
- Do not try to get a suntan
- Do not use sun beds
- Be aware of how much sun exposure your skin is getting. Sitting in direct sunlight between 11:00 and about 15:00 may give you quite a large dose of ultraviolet radiation. You may easily reduce this by sitting in the shade. Close weave clothing, hats, particularly those with a broad brim, and sunglasses are all effective in reducing sun exposure
- Using sunscreen as an addition to the precautions already described may further reduce the amount of ultraviolet radiation reaching the skin
- You should use a sunscreen with SPF (Sun Protection Factor) 30 or higher and ensure that it protects your skin from both the UVB rays that burn and the UVA that cause the damage that results in skin aging. However, using sunscreen may encourage you to stay out in the sun longer because you feel that your skin is protected and they should not be used instead of the measures described above. The only way to protect your skin is by reducing the amount of exposure that you have to a minimum. Sunscreens are the last line of defence!

Vitamin D

Current guidance from NICE (National Institute for Health and Care Excellence) identify that those patients with a diagnosis of a skin cancer may have low Vitamin D levels as they seek to protect themselves from the harmful effects of sun exposure. Vitamin D is needed for healthy bones, teeth and muscles. A daily supplement of 10 micrograms (400IU) is recommended. This is widely available to buy.

Other considerations

There may be situations where you will be asked to complete a health questionnaire. This may include applying for life assurance, a mortgage or when buying travel insurance. You will often be asked if you have had a cancer and we would advise that you answer this question honestly even many years after your skin cancer diagnosis. They may require further information from you or your doctor about this. Withholding information from them could invalidate the policy and mean that you are unable to make a claim.

If you have a critical illness policy you may be able to make a claim following your recent diagnosis.

If you have any questions or concerns about these topics please feel free to discuss them with your Nurse Specialist. Your local Citizens Advice Bureau (CAB) would also be able to advise you on any financial matters.

Section 4 – Your feelings

Your feelings

Everyone reacts differently to being told they have cancer. There is no right or wrong way to feel. Some of the feelings you may experience include shock, fear, anger, guilt, and isolation. You shouldn't expect to feel all of these and you may find that some times are more difficult than others; for example when you are first told that you have melanoma, and prior to any follow up

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appointments. You may find that not only do you experience a range of emotions but also that family and friends may experience them too.

Shock

This is a common immediate reaction. At first you might feel quite numb and unable to accept it has really happened. You may not be able to take in anything which is told to you and may not be able to ask questions. It can take a while for everything to sink in. The numbness may act as a kind of anaesthetic and may enable you to get through all the important practical arrangements. You may also feel detached and strangely calm.

Fear and uncertainty

The word cancer can be very frightening and is often surrounded by myths. It is important to remember that there are many types of cancer and the treatment for each is different. You may find that you become scared about what will happen to you in the future or worried about those close to you and how they will cope.

Denial

Sometimes you do not want to know what is going on, and do not wish to talk about it. You may try to carry on as if everything is normal. This is sometimes a useful mechanism as it allows you time to come to terms with your diagnosis but it can be difficult for those around you to cope with.

Blame and guilt

You may try to look for a cause or reason for having melanoma. It is normal to want an explanation. It can be easy to think that you or someone else is to blame.

Isolation

Sometimes you may wish to be left alone or the fact that you have cancer can make you feel isolated. This can often be the case with melanoma as people are often less familiar with this type of cancer.

Anger

You may feel angry that you have melanoma. This can make you irritable and short tempered and so you may take your feelings out on someone else.

Learning to cope

There are many things which you can do which may help:

1. Try to understand about melanoma and its treatment. Knowing about melanoma will help dispel myths and lessen fear
2. Bring a friend or relative with you to the clinic to listen to what is said, and write down questions you have and bring them with you when you come to the out patient clinic
3. Let family, friends and health professionals know how you feel. Don't bottle up feelings
4. Allow yourself time to come to terms with the diagnosis. Set yourself achievable goals
5. Contact one of the national or local support groups listed at the back of this booklet. It can be a tremendous source of reassurance and encouragement to know that someone else has been through something similar

There are many people who can help:

1. Your Macmillan clinical nurse specialist
2. Your GP and district nurse
3. Local and national voluntary organisations. These groups allow you to meet or talk to others who have experienced cancer. Many offer information, one to one support,

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complimentary therapies, trained counsellors, group meetings. You can contact them anonymously if you prefer

4. **Spiritual help** – many local religious groups offer help and support
5. **Counsellors** – counselling offers the chance to explore your feelings and experiences in a supportive confidential environment. Unfortunately it is not always available on the NHS but you could ask your GP or key worker if you feel you would benefit. You can contact the British Association for Counsellors for a list of counsellors available locally
6. **Patient advice and liaison service (PALS)** – this service is available to help you deal with any concerns you may have whilst visiting University Hospitals Birmingham NHS Foundation Trust. They can support you and your family, provide information on services and listen to suggestions, queries or concerns. They can also help you sort out any problems you may have. The contact telephone number is included at the end of the booklet

Appendices

Medical terms

Cancer

A general term for more than 100 diseases in which cells grow and divide abnormally. Some cancer cells may spread through the blood or lymphatic system to other parts of the body.

Biopsy

The removal of a small piece of skin using local anaesthetic, which is then examined under a microscope to check for cancer cells.

Lymph

Straw-coloured fluid which travels through the lymphatic system. Lymph is derived from fluid in the blood that leaks out of tiny blood vessels and is returned to the circulation by the lymph vessels. Lymph vessels travel up the limbs to lymph nodes.

Lymph nodes

Commonly known as glands. The lymph nodes can filter cancer cells or bacteria travelling through the body in lymph. They may become swollen if they detect infection or cancer cells.

Lymphatic system

The tissues and organs that produce, carry, and store cells that fight infection and disease. This system includes the bone marrow, spleen, thymus, lymph vessels and lymph nodes.

Malignant

Cancerous; a tumour that can spread to other parts of the body.

Melanocytes

Cells which produce a pigment called melanin.

Melanoma

Cancer which arises in the melanocytes. A type of skin cancer.

Metastasise

To spread from one part of the body to another.

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Tumour

An abnormal collection of cells which form a lump. The cells have divided too quickly and without order.

Further information

Further information on health and cancer related topics may be found at The Patrick Centre:

The Patrick Room

Cancer Centre

Heritage Building

Queen Elizabeth Hospital Birmingham

Birmingham, B15 2TH

Tel: **0121 371 3539/3537**

National information web sites:

Macmillan Cancer Relief www.macmillan.org.uk

Cancer Research UK www.cancerresearchuk.org

Important names and telephone numbers

Macmillan clinical nurse specialist.....**0121 371 6777**

Dermatology Outpatients.....**0121 371 5469**

Patient Advice and Liaison Service.....**0121 371 4400**

Skin Oncology Services

Queen Elizabeth Hospital Birmingham

Mindelsohn Way, Edgbaston

Birmingham, B15 2GW

Telephone: 0121 371 2000

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email patientexperience@uhb.nhs.uk.