

Understanding

malignant melanoma

This booklet has been written to help you understand malignant melanoma.

It has been prepared and checked by cancer doctors, other relevant specialists, nurses and patients. The information contained in this booklet represents an agreed view on this cancer, its diagnosis and management, and the key aspects of living with it.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are particularly important for you. You can make a note below of the contact names and information that you may need quickly.

Specialist nurse/contact names

Family doctor

_____	_____
_____	_____

Hospital

Surgery address

_____	_____
_____	_____

Tel

Tel

_____	_____
-------	-------

Treatments

Review dates

_____	_____
_____	_____

If you like, you can also add:

Your name

Address





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The Irish Cancer Society is the national charity for cancer care dedicated to eliminating cancer as a major health problem and to improving the lives of those living with cancer.

This booklet has been produced by the Nursing Services Unit of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment.

We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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■ *Understanding melanoma – key points in this booklet*

This booklet tells you about melanoma, how it is diagnosed and treated and how the treatment may affect you. These two pages sum up the main points and tell you which pages to turn to for more information.

What is melanoma? Page 13

Melanoma is a cancer of the cells in the skin that produce melanin. It usually starts on the surface of the skin, either in a mole or normal looking skin. In rare cases, melanoma can develop in other parts of the body such as the eye, mouth, under the fingernails or toenails or inside the body.

What causes melanoma? Page 14

Exposure to ultraviolet rays from the sun or from sunbeds can damage the skin and can lead to melanoma. You are more at risk if you are fair skinned with red or fair coloured hair and blue eyes. Melanoma is not infectious and cannot be passed on to other people.

What are the signs and symptoms of melanoma? Page 16

- A new lump or mark on the skin that does not go away.
- Change in the size, shape and colour of existing moles.
- Itching, crusting or bleeding of existing moles.

How does the doctor make the diagnosis? Page 16

If your doctor is concerned about an existing mole or a new mark on your skin he or she will remove the mole or affected skin and have it examined under a microscope. This test is called a biopsy and is part of the treatment.

Further tests: Page 19

Depending on the results of the biopsy you may have some or all of the following tests.

What types of treatment are used? Page 23

Surgery is the main treatment for melanoma. In most cases, surgery is the only form of treatment required. However, your doctor may suggest that you have surgery and another form of treatment as well. Special treatment, called immunotherapy, may be used after surgery to reduce the risk of the cancer coming back. Immunotherapy, chemotherapy and radiotherapy may be used to treat melanoma that has recurred or spread to other parts of the body.

How to cope with your feelings? Page 42

You may feel anxious, afraid or angry because of the cancer, the treatment and its effects. The worst fear is the fear of the unknown. It may help you to cope if you find out as much as you can about the cancer, its treatment and living with the diagnosis. Do not be afraid to ask and keep on asking until you get the information and support that you need.

Who can help? Page 54

Many people and organisations can help. There is a list of useful organisations, some books that might help and a list of the most frequently asked questions at the back of this booklet. The Irish Cancer Society's Helpline Freefone 1800 200 700 can give you information about all aspects of cancer and people who can help. The Cancer Helpline is available weekdays 9a.m. - 5p.m.



■ *Introduction*

This booklet has been written to help you find out more about melanoma. By reading this booklet you can learn more about its diagnosis and treatment. We hope it answers some of the questions you may have.

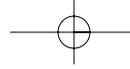
We cannot advise you about which treatment to choose. Only you can make this decision along with your doctor, when all your test results are ready. However, we can help you find out more about some of the methods used to treat this cancer and the side effects that may occur when treatment is given.

This booklet addresses some of the feelings you and those close to you may have when a diagnosis of cancer is made. At the end of the booklet you will find a list of books, which might be useful to read. There is also a list of websites and special groups that have been formed to help and support you at this time. The Cancer Helpline Freefone at 1800 200 700 can also give information about all aspects of cancer and people who can help.

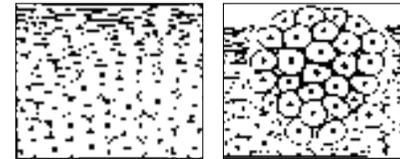
If reading this booklet helps you, why not pass it on to your family and friends who might find it helpful too. The more they know about your illness the more they will be able to help you cope.

■ What does that word mean?

Abdomen	The part of the body that lies between the chest and the hips. Sometimes known as the belly or tummy.
Adjuvant treatment	Treatment given soon after surgery when a diagnosis of cancer is made.
Alopecia	Loss of hair. No hair where you normally have hair.
Anti-emetic	A tablet or injection to stop you feeling sick or vomiting.
Benign	Not cancer.
Biopsy	The removal of a small amount of tissue from your body to find out if cancer cells are present.
Cell	Cells are the building blocks that make up your body. They are very small and are only seen under a microscope.
Chemotherapy	Treatment using anti-cancer drugs.
Fatigue	Tiredness.
Immunotherapy	Treatment using drugs which affect the immune system.
Nausea	Feeling sick or wanting to be sick.
Malignant	Cancer.
Metastasis	The spread of cancer from one part of the body to other tissues and organs.
Oncology	The study of cancer.
Medical Oncologist	A doctor who specialises in treating cancer patients using chemotherapy.
Radiotherapy	The treatment of cancer using high energy X-rays.
Radiation Oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Staging	A series of tests that measure the size and the extent of the cancer.



■ What is cancer?



Normal cells

Cells forming a tumour

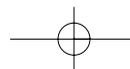
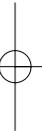
Cancer is a word used to describe a group of diseases. Each one has its own name. For example: colon cancer, lung cancer, and breast cancer. Each has an individual type of treatment and chance of being cured.

The organs and tissues of the body are made up of tiny building blocks called cells. All cancers are a disease of the body's cells. In healthy tissue these cells repair or replace themselves when they get worn out or injured. When there is cancer the cells do not behave as normal and keep on growing even when they don't need to.

These abnormal cells can form a tumour. Tumours are either benign or malignant. Benign tumours do not spread to other parts of the body so are not called cancer. Malignant tumours are made up of cancer cells that can spread from where they started and can go on to interfere with other tissues and organs. This may happen when a cell or group of cells breaks away and enters the blood stream or lymphatic vessels to form a new tumour somewhere else in the body. This is called a **metastasis** or **secondary tumour**.

The lymphatic system

The lymphatic system is one of the body's natural defences against infection. It includes a network of tiny tubes like blood vessels, which pass through almost all the tissues in the body. These vessels carry a clear watery-like fluid called lymph. This lymphatic



fluid contains infection-fighting cells called lymphocytes. Along this network are hundreds of small bean shaped glands called lymph nodes. Their job is to filter the lymphatic fluid for foreign particles as it passes through. This allows the lymphocytes to interact so that they can function to protect the body against infection.

Lymph nodes are found in groups throughout the body such as in the neck, armpits and groin. Sometimes you may become aware of these glands if they become swollen or enlarged. More of these lymph nodes are found grouped together in the chest and abdomen. Other parts of the lymphatic system include the spleen, thymus, tonsils and bone marrow.

To sum up

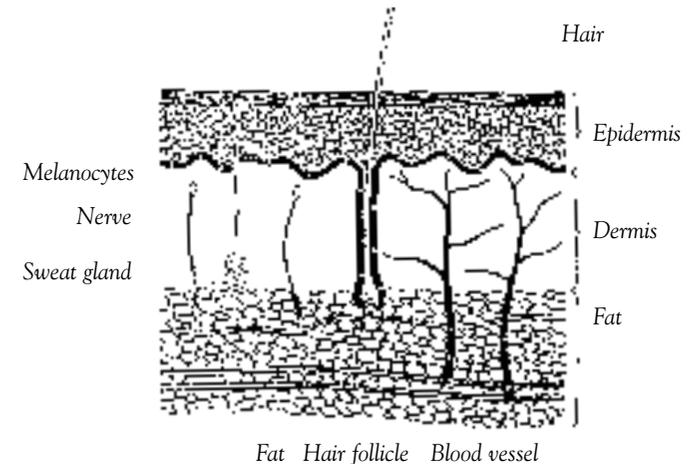
- Cancer is a disease of the cells of the body.
- Where there is cancer, cells do not behave as normal and keep on growing even when they don't need to.
- These abnormal cells can form a tumour.
- Cells may break away from a malignant tumour and enter the blood stream or lymphatic vessels to form a new tumour somewhere else. This is called a **metastasis** or **secondary tumour**.

■ The skin

The skin is the largest organ in the body. It consists of two main layers, the epidermis and the dermis. The top layer, the epidermis contains cells called melanocytes. These cells produce a pigment called melanin, which is responsible for the colour of skin. Melanin helps to protect the skin against damage from the ultraviolet rays found in sunlight. In fair skinned people the amount of melanin present in the skin is small. The lighter the colour of the skin the more easily it can be damaged by sunlight. As well as producing melanin the skin has other functions. These include:

- The skin protects the body from injury and infection.
- It helps to regulate body temperature.
- Waste products such as salt and other minerals are removed from the body through the skin.

The skin



■ *What is a mole?*

A mole is a group of melanocytes that come together to form a mark on the skin. There are several different types of mole. The most common ones are birthmarks and ones that develop on the skin during childhood.

Birthmarks

Birthmarks are very common. They are small brown or black marks that can be found on a child's skin at birth or soon after they are born. Most birthmarks get slightly bigger as a child gets older. They may also become darker in colour. Most birthmarks are harmless. However, if a birthmark suddenly gets darker, larger or lumpy, or starts to bleed, go and see a doctor straight away. He or she will tell you what to do.

Ordinary moles

These are small brown or black marks that are found on the skin. These appear on the skin during childhood. Like birthmarks, they are usually harmless. Most people have 20-40 small brown, or slightly raised moles. They are painless and most people are aware of them. When they first appear they are flat, brown circles or oval shaped on the skin.

As you get older they may change slightly, becoming darker in colour and raised above the surface of the skin. Most moles are quite normal and should be left alone. However, if a mole suddenly shows a change in size, shape or colour and/or starts to bleed you must have it checked out by a doctor. You may need to have it removed. Go and see a doctor as soon as possible. He will advise you what to do.

■ *What is melanoma?*

Malignant melanoma or melanoma as it is called throughout this booklet, is a cancer of the cells in the skin that produce melanin. It usually starts on the surface of the skin, either in a mole or normal looking skin. In rare cases, melanoma may develop in other parts of the body such as the eye, mouth, under the fingernails or toenails or inside the body. If it is diagnosed and treated early there is a very good chance of cure. However, melanoma may spread to other parts of the body through the lymph channels or bloodstream. It may also spread within the skin itself.

The four main types of melanoma are:

- Superficial spreading melanoma. This type of melanoma usually grows along the surface of the skin. It may arise out of a mole that has suddenly changed in appearance. This is the most common type of melanoma.
- Nodular melanoma. This melanoma grows more quickly. It may arise out of normal looking skin. Nodular melanoma is more common in men.
- Lentigo maligna melanoma. This type of melanoma can be found on the faces of elderly people. It can grow very slowly and may take years to develop.
- Acral melanoma. This melanoma is usually found on the palms of the hands, soles of the feet or around the toenails. It is more common in dark skinned people.

Melanoma can affect most parts of the body. It is more likely to be found on the legs in women and on the back or trunk in men.

Melanoma of the eye

Rarely, melanoma develops in the lining of the eyeball, which is called the uvea, and is known as uveal melanoma.

Signs and symptoms

Symptoms include blurred vision, seeing flashing lights and shadows. All these symptoms are common to other conditions of the eye. In most cases, it is possible for an eye specialist to detect the tumour by looking at the back of the eyeball with a special instrument.

Treatment

The aim of treatment is to preserve as much of the vision as possible. Treatment may include radiotherapy, laser therapy, surgery and drug treatment. Your doctor may decide not to give you treatment straight away but bring you back for regular checkups so that the tumour can be monitored.

■ *What causes melanoma?*

The main factor thought to cause melanoma is the exposure of white skin to strong sunlight. The type of skin you have and your life time exposure to the sun may also increase your chances of developing melanoma. The risk of developing melanoma can be greatly reduced by simply avoiding sunburn and deep tanning. There is also an increased risk of getting the disease if there is a history of melanoma in your family.

Skin type

People with white skin that does not tan easily or that burns quickly in the sun are more at risk of developing melanoma.

This type of skin usually goes with fair or red hair and blue eyes. If you have had melanoma in the past you may also be more at risk. People with large numbers of moles or moles that are unusual may have an increased risk of developing melanoma.

Sun exposure

Melanoma is rare in childhood. However, severe sunburn or blistering as a child may increase the risk of developing it later on in life. Sudden exposure of pale skin to strong sunlight will increase the risk of burning and skin damage. If you are fair skinned you are more at risk if you work outside or play a lot of outdoor sports and do not use a sunscreen or wear protective clothing.

Sunbeds

Artificial sunlight may be as damaging to your skin as natural sunlight. Sunbeds use UVA rays to tan the skin. UVA rays may cause little of the skin redness and peeling that is normally seen after exposure to natural sunlight so you may not be aware of the damage you are doing to your skin. If you have fair skin that burns easily you will find it difficult to get a tan when using a sunbed. It may give you mild protection from sunburn when exposed to natural sunlight. However, it does not protect you from long-term skin damage. Using a sunbed at regular intervals will cause skin damage. It may also increase your risk of developing melanoma.

■ *What are the signs and symptoms of melanoma?*

The main signs may include one or more of the following:

- You have a mole that suddenly gets bigger or you find a new one on your skin.
- The mole has developed a ragged or uneven outline.
- The mole has a mixture of different shades of brown, black or other colours through it.

Other symptoms might include:

- The mole is bigger than the blunt end of a pencil.
- It looks red or inflamed around the edges.
- The mole is bleeding, oozing or crusting.
- It starts to feel different: for example, slightly itchy or painful.

If you have any of the above signs and symptoms you must have them checked out by your doctor as soon as possible. He or she will examine you and decide what to do. Melanoma has a very good chance of being cured if diagnosed and treated early.

■ *How does the doctor make the diagnosis?*

Most people begin by visiting a doctor. If the doctor has concerns about you, he or she will refer you to a skin specialist (dermatologist) or surgeon. The doctor will ask you some questions about your health and examine your skin.

In most cases, the specialist can tell whether the mole is benign or malignant straight away. If there is any doubt, he or she may suggest a biopsy of the skin. The doctor will remove all or some of the mole or affected skin under a local anaesthetic. Sometimes a biopsy is the only treatment required for melanoma. Your doctor may send you for a chest X-ray and some blood tests to check your general health.

skin biopsy

A skin biopsy normally causes very little pain. However, the local anaesthetic used to numb the skin can sting a little as it is being given. When you are ready a small cut is made through the skin, and all or some of the mole or affected skin is removed. At least one centimetre of normal looking skin around the affected area is removed as well. This is to ensure that if there are melanoma cells present none are left behind. The skin sample is looked at under a microscope to see if there are any cancer cells present. You may need a couple of stitches after the biopsy. The biopsy only takes 5-10 minutes. It's a good idea to have someone to take you home after the procedure, as you may feel a little tired. The result of the biopsy is usually available within 5-10 days.

■ *What happens next?*

What happens next depends on the results of the biopsy. The biopsy result will show if you have melanoma and if you have, whether it has been completely removed. It will also show how deep it extends below the surface of the skin and if you need further tests or treatment.

Early melanoma

If the melanoma has been completely removed, and did not extend too deeply below the surface of the skin, your doctor may decide that no further treatment is necessary. However, you will have to attend your doctor at regular intervals to have your skin examined. Melanoma can recur and if you have been treated for melanoma you are more at risk of developing it at the same place or elsewhere on the body. Your doctor may want to see you quite often at first but the visits will decrease with time. At these visits the doctor will examine your skin and the lymph nodes in your neck, armpits and groin.

You will also have to learn how to inspect your skin. Your doctor will show you how to do this. It is very important that if you develop a new melanoma, it is diagnosed and removed as soon as possible. Early diagnosis of melanoma improves the chance of successful treatment. If you are between check-ups and you have a problem that concerns you, let your doctor know by making an appointment to see him or her as soon as possible.

■ *Staging*

Your doctor may want to do further tests if it was not possible to remove the entire melanoma or if it extends below the surface of the skin. This is known as staging. These extra tests are most important, as they will show if the melanoma has spread to other parts of the body. The results of the tests will help your doctor to decide on the best treatment for you.

Cancer cells can sometimes spread to the lymph glands close to site of the melanoma. This is unlikely to happen if the melanoma

is less than 1 mm thick. If the melanoma cells extend more than 1mm into the skin, your surgeon may do a test during surgery to try to find out whether the melanoma has spread to the lymph nodes. This test is called a sentinel node biopsy.

sentinel node biopsy

A tiny amount of radioactive liquid/dye is injected around the area of the melanoma before it is removed. The radioactive liquid will highlight lymph nodes that contain melanoma cells. The lymph nodes are then scanned to see which, if any, has taken up the radioactive liquid. The first node to take up the radioactive liquid is called the sentinel node.

If the sentinel node contains melanoma cells all the lymph glands in the area are removed. This procedure is explained on page 24. If there are no melanoma cells present in the sentinel lymph node it is unlikely that other lymph nodes are involved. Further treatment is usually not required.

The risk of problems following a sentinel node biopsy is very low, and they tend to be mild. Some people develop infections at the biopsy site and may need to take antibiotics after the test. Fluid or blood may collect in the biopsy site and may need to be drained off. These problems are temporary and usually clear up within a few weeks of the procedure. There is a very small chance of lymphoedema (swelling in the area) following a sentinel node biopsy.

Further tests

The tests may include all or some of the following:

- CT scan
- Ultrasound of liver and abdomen



A patient undergoing a CT scan

- Bone scan
- MRI scan

CT scan (CAT scan):

This is a special type of X-ray that builds up a detailed picture of the inside of your body.

Preparation for a CT scan can vary. The doctor or nurse in your hospital will tell you what to do. You may have to fast for 4 hours before the scan.

You may be given a special drink or injection

which helps show up parts of the body on the scan. It is important to let the radiographer know if you are allergic to iodine or have asthma before you take the drink or injection. The injection may make you feel hot all over for a few minutes. CT scans are painless and normally take about 30 minutes to complete. This test is usually done as an outpatient.

Ultrasound of liver and abdomen: This test is carried out in the X-ray department of the hospital. A picture is built up of the inside of the liver and upper abdomen using sound waves. You will be asked to lie on your back and gel will be spread over the area to be scanned. A small device like a microphone, which produces sound waves, is used to take the scan which is converted into a picture by a computer. This test is painless and takes about 10 minutes.

Bone scan: Bone scans are very sensitive and can detect cancer cells before they show up on X-ray. For this test a very small amount of mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken of all the bones in your body. As abnormal bone absorbs more of the radioactive substance than normal bone, this shows up on the scan as highlighted areas. After the injection you will have to wait for up to three hours before the scan can be taken, so you may want to take a book or magazine with you, or a friend to keep you company. The level of radioactivity used in these scans is very low and is not harmful. The radioactivity disappears from the body within a few hours.

MRI scan: This is a special scan that uses magnetic energy to build a picture of tissues inside the body. It does not hurt but can be very noisy. Ask for earplugs to wear during the test. You may have an injection before the scan to highlight certain areas of the body. You cannot wear metal jewellery during the scan and patients who have certain medical devices implanted are not suitable for the test. The doctor in the hospital will advise you. Most people can go home after the scan.

These tests will show extent of the disease and help your doctor decide on the best treatment for you.

It will take about a week for all the test results to come back. This is an anxious time for you. It may help to talk things over with a relative or close friend. You may also wish to call the Cancer Helpline Freefone 1800 200 700 to speak to one of our specially trained nurses.

■ *Further treatment*

Depending on the results of the tests, your doctor may recommend that you receive further treatment.

The kind of treatment chosen for you is based on many factors. These include the type and size of the melanoma, where it is located, and whether there is any other organs involved. Your doctor will also consider your general health. A team of specialist doctors will then plan your treatment.

Locally advanced melanoma

Sometimes it is not possible to remove all the melanoma at time of biopsy. In this case, you may have to have further surgery. You may require a skin graft if the surgeon has to remove a large area of skin around the melanoma. Your doctor may decide to give you additional treatment even if the melanoma is confined to one section of skin. This is because, due to the thickness or size of the melanoma, there is a high risk that it may return.

Your doctor will talk to you and tell you about your treatment choices.

You may notice that other people with melanoma are not getting the same treatment as you. Their cancer may not be at the same stage as yours and their treatment needs are different. At this time you may be anxious about what is going to happen next. Talk to your doctor. You may want to use the blank page at the back of this booklet to write down your questions and the answers you receive. Your doctor will talk to you and tell you about your treatment choices.

Melanoma that has spread to other parts of the body

If the melanoma has spread to other parts of the body you will require further treatment.

The treatment recommended to you will depend on the extent of the cancer, which organs are affected and your general health. Your doctor may suggest further surgery if the cancer has spread to the lymph nodes. Immunotherapy and chemotherapy can also be used. Radiotherapy may be used if the brain or spinal cord is affected or to relieve pain.

■ *Surgery*

Sometimes it is not possible to remove all the melanoma at time of biopsy. In this case, you will have to have further surgery. If the melanoma is quite big you may have to have a skin graft to replace the skin that was removed

skin graft

If you need to have a skin graft the surgeon will take a layer of skin from another part of your body and place it on to the wound. The thickness of the skin taken depends on the depth of the area to be covered.

Once the skin is in place it is covered with a dressing. The graft is checked after several days to make sure it is healing properly. The area from where the skin is taken from is also checked and dressed regularly. You may feel sore for a few days after your operation. Your doctor will prescribe painkillers for you.

You can go home when the skin graft and the area from where the skin was taken are well healed. This is usually 7-10 days after the operation. You may have to come back to the hospital for dressings. The graft area is not pleasant to look at to begin with but will heal and fade in time.

Removal of lymph nodes

If melanoma cells are found in the lymph nodes your doctor may decide to remove some of the nodes. Removing the lymph nodes may help to prevent the cancer spreading to other parts of the body.

The lymph nodes are removed in hospital under a general anaesthetic. You may feel sore for the first few days after the operation but most people recover quickly. In a very small number of cases swelling may occur at the site of the removed lymph nodes. This is called lymphoedema. Wearing elastic support garments can ease this swelling. There is a booklet about lymphoedema available. Call the Cancer Helpline Freefone 1800 200 700 for a copy.

To sum up

- Surgery is the main treatment for melanoma.
- The aim of surgery is to remove the entire melanoma.
- In most cases, surgery is the only form of treatment required.

■ *Immunotherapy*

Immunotherapy is a treatment that can stimulate the body's immune system to fight cancer cells. One of the drugs used is called Interferon. Your doctor may decide to give you a course of Interferon if you have had a melanoma removed but there is a high risk of it recurring. It can also be used to treat melanoma that has recurred or spread to other parts of the body.

Treatment is usually given as a small injection under the skin. The drug is injected three days a week or once every day. However, it can be given directly into a vein or as an intravenous infusion. You may need to stay on treatment for up to a year or more. Your doctor or nurse can show you or a relative how to inject the drug or they can give it to you. Your doctor or nurse will explain how often you should take the drug and how long treatment will last, as this can vary from person to person.

Before you start treatment ask your doctor about the side effects that you can expect.

Interferon can cause side effects similar to flu symptoms including chills, fever and headaches. You may feel very tired. It may help to take the injection in the evening or late at night so that the side effects occur while you are resting or asleep. Before you start treatment ask your doctor about the side effects that you can expect. He or she will tell you what you can do to make treatment easier. For most people the side effects soon disappear once the treatment is over.

To sum up

- Immunotherapy can be used to treat melanoma.
- Treatment is usually given as a small injection under the skin.
- You may need to stay on treatment for a year or more.

■ Chemotherapy

Chemotherapy is a treatment using drugs that cure or control cancer. These drugs are used on their own or in combination. Chemotherapy can be used to treat melanoma that has spread to other parts of the body at time of diagnosis or melanoma that recurs following initial treatment. Most patients with melanoma who need chemotherapy will get a combination of three or four drugs. Chemotherapy may be given before or after radiotherapy. It can also be given after surgery.

The drugs used in chemotherapy travel through the blood stream to almost every part of the body. They are often given in cycles such as once every 2 to 4 weeks. There is usually a rest period between each course of treatment. This allows the body time to recover from the effects of the drugs. Each visit to hospital for treatment is called a cycle. The number of cycles you have will depend on how well the melanoma is responding to treatment.

Chemotherapy may be given by direct route into a vein as an injection or through an intravenous infusion (drip). It may also be given in tablet form. You may have to stay in hospital overnight for treatment. However, some treatments are given in day-care.

The drugs used include Dacarbazine, Cisplatin and Carmustine. Before your chemotherapy is given, your doctor will discuss your treatment options with you.

■ Side effects of treatment

The side effects of chemotherapy vary from one person to another and depend on the drugs used. It is possible to have this treatment and have side effects that are well controlled with medication. These unwanted effects happen because while the chemotherapy is working on the cancer cells it can have an effect on normal cells too.

Before you start your treatment ask your doctor about any side effects that may occur. Do tell your doctor about the way you are feeling during your treatment as most side effects can be eased with medication. In most cases, the side effects go away when the treatment ends or soon after. Your doctor or nurse can give you something to stop most of them or make them easier to cope with.

Infection

Chemotherapy can make you more likely to get infections. This happens because most chemotherapy drugs affect the bone marrow, which makes the white blood cells that fight infection. If you do not have enough white cells, even a minor infection such as a cold or a sore throat could make you quite ill. During each treatment cycle you will have blood tests to make sure that you have enough white blood cells.

If you are feeling shivery and unwell or running a temperature of 38° C or higher, tell your doctor straight away.

Your doctor will ask you to watch out for signs of infection at all times especially if your white cell count is low. These signs could include feeling shivery and unwell or running a high temperature of 38° Celsius (100.3 Fahrenheit) or higher. If this happens tell your doctor straight away. He or she will tell you what to do. Some hospitals prefer you to ring them directly. Check this out with your nurse or doctor before you start treatment. If you have a high temperature or feel unwell, you

will need to have a blood test to check if your white cells are low. You may need medication to treat the infection.

As you will be more at risk of picking up infections while on treatment, try to avoid close contact (such as hugging or kissing) with people who have colds or flu and other infections such as chicken pox, shingles or measles. Let your doctor know if you are in contact with these or any other infections. Wash your hands often during the day, especially before you eat and after going to the toilet. Infection is a serious complication of chemotherapy. You will need treatment as soon as possible. Talk to your doctor or nurse. They will give you more information.

Feeling sick (nausea) or wanting to be sick

Not everyone feels sick or gets sick with chemotherapy, but if you do it can happen before, during or after treatment. It may last for several hours. There are very effective drugs available now that prevent or reduce nausea and vomiting. Ask your doctor to give you medication to stop you feeling sick. Take your medication as directed by your doctor.

Let your doctor or nurse know if the drugs are not working as they can be changed.

Sore mouth

Some drugs used to treat melanoma can cause a sore mouth. They can also cause little ulcers to appear on the tongue, gums and inside the cheeks of your mouth. Try to keep your teeth, gums and mouth very clean, as this will reduce the risk of getting a mouth infection. Clean your teeth after each meal. Use a soft toothbrush. If you have dentures remove them if your gums are sore. There are

special mouthwashes that you can use. Your nurse will show you how to use them properly.

Not wanting to eat

It is best to eat as much you can while on chemotherapy. You may become tired and unwell if you are not eating properly. Eat smaller amounts more often. If you do not feel like eating during treatment, you could try replacing some meals with special food supplements. The dietician will be available to advise you.

Fatigue

You may feel very tired. This tiredness can last for some weeks after treatment has ended. If this happens take things easier. Do less than you would normally do. Rest more if you can. Ask your family or friends to help you at work or at home. For more information on fatigue turn to page 36.

Numbness or pins and needles in the hands and feet

Some chemotherapy drugs used to treat cancer can cause tingling or burning sensations in your hands and feet. You may also have trouble in picking up small objects or buttoning up a shirt or cardigan. This effect is almost always temporary and goes away after treatment stops. However, do tell your doctor if this happens, as some changes may need to be made to your treatment.

Hair loss (alopecia)

You may notice that your hair thins out a little. It is not usual for your hair to fall out completely. If you do lose your hair it normally occurs about 2-3 weeks after your first cycle of chemotherapy. Try not to worry, as your hair will start to grow again when treatment

stops. You may feel upset at the thought of losing your hair. Talk to your nurse or social worker about your feelings. He or she will help you find ways to cope with hair loss. You can get a wig when this happens or you may prefer to wear a hat, turban or scarf.

If you would like a wig, talk to your social worker or nurse. He or she will provide you with the names and addresses of wig fitters. Your local hairdresser may also help. In some cases it is possible to get financial assistance towards the cost of a wig. Ask your social worker or nurse. For most patients the amount of hair loss is small. A wig is not always needed.

If you are concerned about other side effects or symptoms, talk to your doctor or nurse straight away. He or she will tell you what to do.

To sum up

- Chemotherapy is a treatment using drugs to cure or control cancer.
- The drugs can be given in tablet form, directly into a vein as an injection or through an intravenous infusion (drip).
- The side effects vary from person to person depending on the drugs used. Most side effects are well controlled with medication.

■ Radiotherapy

This is a treatment where high energy X-rays are directed at a cancer to cure or shrink the cancer. Radiotherapy is not commonly used to treat melanoma when it is confined to the skin. It is used more often if the cancer recurs or spreads to other parts of the body such as the brain or spinal cord. Radiotherapy can also be used to relieve pain.

Planning your treatment

Before radiotherapy, your doctor and other specialists, plan how best to deliver your treatment. They decide how much radiotherapy is needed to treat the cancer while doing the least possible damage to normal cells.

Before your treatment can begin you will be marked on the skin where the treatment is to be delivered. This is done with ink or a permanent tattoo. The X-rays are then directed at the same area each day. Any marks made with ink should not be washed off until treatment is over.

Treatment planning is a very important part of radiotherapy and it may take a few visits before your treatment can go ahead. Before starting radiotherapy you will be told how to look after your skin during and after treatment.

Getting your radiotherapy

Having radiotherapy is quite straightforward. You will have to come for treatment every day during the week with a rest at weekends. Your treatment can go on for 2-4 weeks. Each treatment session only takes a few minutes. You will not feel any pain while you are getting treatment but you will have to lie still. How much treatment you receive will depend on the size and location of the cancer. Your doctor will discuss this with you.

Each time you go for treatment you will go into a radiotherapy room. The radiation therapist will ask you to lie or sit in a certain position under a radiotherapy machine called a linear accelerator. When you are ready he or she will leave the room. The machine is then turned on and your treatment given.

Even though you are on your own in the room your radiographer can see you all the time through a closed circuit camera. You can talk through an intercom if you need to.

Will I have any side effects?

Radiotherapy is given directly to the site of the cancer. Therefore, the side effects that occur are related to the part of the body being treated. The severity of the side effects will vary from person to person and depend on the amount of treatment received.

External radiotherapy does not make you radioactive. It is perfectly safe for you to mix freely with family and friends.

Radiotherapy to the skin alone has few side effects. The area being treated may become a little red for a few weeks and a scab may form over the area. Radiotherapy given to parts of the body that have hair, such as the head, may cause hair loss. The hair may grow back once treatment is over.

If you would like more information on radiotherapy there is a booklet available. Call the Cancer Helpline Freefone 1800 200 700 for a copy.

External radiotherapy does not make you radioactive. It is perfectly safe for you to mix freely with family and friends.

To sum up

- Radiotherapy is the treatment of cancer using high energy X-rays.
- You will not feel any pain while you are getting treatment. Each session only takes a few minutes.
- Treatment may continue for 2-4 weeks depending on the extent of the cancer.

■ *What effect will treatment have on your sex life?*

There is no medical reason why you cannot have sex while on chemotherapy or radiotherapy if you feel like it. However, coming to terms with the fact that you have cancer can take quite a while. Your emotions are often turned upside down. It is hard to relax when you have a lot on your mind. You may also feel tired from the effects of treatment. As a result, you may become disinterested in sex. This is a normal way to feel at this time. One common fear is that cancer can be passed on to your partner during intercourse. This is not true. It is perfectly safe for you to resume a sexual relationship.

Even if you do not feel like having sex you can still enjoy a close and loving relationship.

There is no set time for you to be ready to have sex again. It varies from person to person. Once you return to your usual routine your interest in sex should return. If you have a supportive partner, you may find that talking about your feelings will help ease your anxiety. Even if you do not feel like having sex you can still enjoy a close and loving relationship. You should not feel guilty or embarrassed to talk your doctor or nurse about what is troubling you; he or she may refer you for specialist counselling if you think that would be helpful.

Will treatment affect my fertility?

Some treatments for melanoma can cause infertility. This infertility may be temporary or permanent. Your doctor will talk to you about this in more detail before you start your treatment. If you have a partner, you may find it helpful if you see the doctor together so that you can both talk about your fears and worries.

Immunotherapy and chemotherapy

For women

Your doctor may recommend a course of immunotherapy or chemotherapy if you require further treatment for melanoma. Some of the drugs used to treat melanoma can affect the ovaries and may cause infertility. It may be temporary or permanent. This means that your periods may stop during and for a few months after treatment. You may get hot flushes, a dry vagina or other symptoms of the menopause (change of life). If it is temporary, your periods will return to normal after a few months. In general the younger you are, the more likely it is that regular periods will return. The nearer a woman is to her menopause the more likely it is that chemotherapy will stop her periods permanently.

As periods usually stop while you are on treatment you may not know whether you are fertile or not. If you are having sex and are still young enough to have children you must use some reliable method of contraception throughout and for some time after your treatment. There is a risk of miscarriage or birth defects in babies conceived during or just after treatment. Many doctors believe it is better not to get pregnant for three years after your chemotherapy ends. This gives you a chance to recover from the effects of treatment and by this time the likelihood of the cancer coming back is much less.

When treatment is over you can have blood tests to find out if you are fertile or if you have started the menopause. Talk to your doctor or nurse. He or she will answer your questions in more detail.

For men

Some of the drugs used to treat melanoma may cause infertility. It may be temporary or permanent. If you are having sex and your partner is still young enough to have children you must use some reliable method of contraception throughout your treatment and for some time afterwards. This is because there is a risk of miscarriage or birth defects in children conceived during or just after treatment. Many doctors believe it is better for your partner not to get pregnant for three years after your chemotherapy ends. This time gives your body a chance to recover from the effects of treatment and by this time the likelihood of relapse is much less.

During and after radiotherapy

Most radiotherapy treatment to the skin has no effect on your ability to have children. Radiotherapy to other parts of the body may make you feel tired and less interested in sex. Many specialists recommend that you wait for three years after radiotherapy before trying to start a family or to have more children. This time gives your body a chance to recover from the effects of the cancer and its treatment.

■ *Fatigue*

Fatigue is something that many people complain of from time to time even if they are not ill. For most people it is nature's way of telling them to slow down and take some rest. Fatigue is a common symptom of cancer. It is often described as an overwhelming tiredness. You may find it difficult to concentrate or make decisions. The reason for fatigue is sometimes hard to identify. Fatigue may be caused by anxiety and worry when a diagnosis of cancer is made and the additional stress caused by treatment. It is important to know that even though you may find it hard to identify the reasons for your tiredness there is something you can do to help.

What you can do

- For many patients treatment may help by relieving symptoms such as pain and fatigue allowing you to get back to your normal routine. Ask your doctor before you start treatment what side effects you can expect.
- If you are feeling worried and find it hard to sleep at night tell your doctor or nurse. He or she will help you. Try talking to your close family or friends about your concerns. If you find this difficult ask to see a social worker or counsellor. He or she will help you to find ways to cope.
- If your illness allows you to take part in physical exercise, try to do some on a regular basis. For example, 30 minutes exercise three days a week might be a realistic goal and will boost your morale when you achieve it.
- You may notice that you have lost weight. This may be due to the cancer or the treatment you are getting. Sometimes when you are feeling weak and tired you may lose interest in your

food. Ask for help in preparing your meals. Eat your favourite foods. Take plenty of clear fluids such as water or fruit juice.

- Get others to help you around the house, with the travelling to hospital, with the children or with shopping.
- Whether you work or not during treatment will depend on the kind of work you do and how you are feeling. It is probably better to make this decision when you have had one or two courses of treatment. You will then have a better idea of how the treatment affects you.

There is a booklet, *Understanding Fatigue* available. If you would like more information, call the Cancer Helpline Freephone 1800 200 700 for a copy.



■ *Research – what is a clinical trial?*

Research into new ways of treating melanoma is ongoing. Surgeons are investigating how much skin needs to be removed around a melanoma. In some cases, it may prove possible that in melanomas of a certain size and thickness, a skin graft is no longer required. Some researchers are looking at new anti-cancer treatments for melanoma that has spread to other parts of the body, while others are looking at new ways to stop or slow the spread of cancer.

The best time to give chemotherapy is also being investigated. Many new chemotherapy drugs are being tested for their effectiveness in the treatment of melanoma. Doctors are also investigating the use of high-dose treatments in groups of patients who, in the past, were not thought to be suitable for this type of treatment.

To date, one of the problems with chemotherapy and radiotherapy is that the amount of treatment you can get is limited. This is because that along with killing cancer cells, these treatments damage healthy tissue as well. On-going research is looking at new treatments that destroy cancer cells with little or no effect on healthy tissues. These treatments include the use of vaccines and drugs that may help the immune system to fight the cancer. Research into vaccination to prevent melanoma recurring is also taking place.

Your doctor may suggest that you to try a new form of treatment. Doctors can only improve the treatment of cancer by trying new treatments on carefully selected groups of patients. These are called clinical trials. Sometimes, several hospitals take part in the same clinical trial. The more people who take part in a trial the

more useful the findings will be.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been explained to you, so that you understand what the trial is about. This is called **informed consent**. You will also need time to think about it and discuss it with your family and friends. By taking part in a trial you may not benefit yourself, but you may help to improve the prospects of other patients in the future. If you decide not to take part you will be given the best treatment currently available.

If you would like to find out more about clinical trials, there is a booklet available.

Call the Cancer Helpline Freefone 1800 200 700 for a copy.

Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind.

Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind.

■ *Follow up*

Whatever treatment you receive for your cancer you will have to come back for regular check-ups. In the beginning these may be quite often. Visits may include seeing your doctor and having your skin examined. You may also have tests such as X-rays, scans and blood tests carried out at regular intervals. These will continue for a number of years but will become less frequent as time goes by.

If you are between check-ups and you concerned about an existing mole or a new mark on your skin make an appointment to see your doctor as soon as possible.

■ *Cancer and complementary therapies*

You may hear about the following types of treatments or therapies. It is important to know what they are and how they might help you.

Conventional therapies

Conventional therapies are the treatments which doctors use most often to treat people with cancer. These consist of surgery, radiotherapy, chemotherapy and hormone treatments. All these treatments have been tested in clinical trials and there is long experience with patients.

Complementary therapies

Complementary therapies are treatments that are sometimes given **alongside** the conventional treatment.

They include:

- Therapies such as psychotherapy, relaxation and visualization.
- Therapies which many people find helpful such as gentle massage, aromatherapy and reflexology.

Many people who have cancer find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. They may help you to cope better with the physical side effects of cancer and the often-distressing emotions that cancer can bring.

Alternative therapies

Alternative therapies are sometimes used instead of conventional

treatments. These therapies include: diet therapy, megavitamin therapy and some herbal medicines. Most doctors do not believe that such treatments can cure or control cancer. It is possible to spend large amounts of money and time on treatment that may result in more harm than good to the patient with cancer.

If you are thinking of going for treatment with either a complementary or alternative practitioner, it is important that you discuss this with your cancer specialist.

You should also ensure that the practitioners you are planning to visit are properly qualified and will charge a fair price for your treatment. There is a booklet available on complementary therapies. If you would like more information call the Cancer Helpline Freefone 1800 200 700



Complementary therapies are treatments that are sometimes given alongside the conventional treatment.

■ *How to cope with your feelings*

You might feel numb and shocked when you are told that you have cancer. You can feel swamped with many different emotions ranging from disbelief to anger. At first the news may be very hard

to take in. It may all seem 'unreal'. All these feelings are normal and to be expected. It does not mean that you are not coping. Rather they are part of the process you must go through in coming to terms with your illness. Your family and friends may also feel the same way and need time to get used to it.

Reactions differ from one person to another – there is no right or wrong way to feel.

Reactions differ from one person to another – there is no right or wrong way to feel.

Shock and disbelief

'I can't believe it.' 'It can't be true.'

Shock is often the first reaction when a diagnosis of cancer is made. Most people think, 'It will never happen to me.' It will take a while for the news to sink in. At this stage you may be getting a lot of information about your illness. You may ask the same questions over and over again or seem to accept the news calmly. These are common reactions to a diagnosis of cancer. Because you don't quite believe what is happening, you may not want to talk about your illness, especially to your close family and friends.

Fear and uncertainty

'Am I going to die?' 'Will I be in pain?'

For most people when they are told they have cancer the first question is 'Am I going to die?' Cancer is a very scary word.

It brings to mind many stories – most of them untrue. In fact nowadays many cancers can be cured. When cure is not possible the cancer can be controlled for a number of years by using modern treatments. There are new treatments being developed all the time.

Another common fear is that cancer is always painful. This is not true. Some cancers cause no physical pain at all. If you do get pain there are many drugs that can control it. Other methods of pain relief include radiotherapy and nerve blocks. Being concerned about your future is a normal way to feel. It can be hard for your

doctor to predict the outcome of your treatment. Not knowing can make you feel anxious. The more you find out about your illness and its treatment, the less anxious you will be.

The real facts about cancer and its treatment are not as frightening as you might imagine. Talk to your doctor about your concerns, he or she should be able to help you. Discuss what you have found out with your family and friends, as they are probably worried too.

The real facts about cancer and its treatment are not as frightening as you might imagine.

Denial

'There is nothing really wrong with me.' 'I haven't got cancer.'

Many people cope with their illness by not wanting to talk about it. If that is the way you feel then just say quite firmly to the people around you that you would prefer not to talk about your illness, at least for the time being.

Sometimes, however, it's the other way round. You may find it is your family and friends who are denying your illness. They appear to ignore the fact that you have cancer. They may play down your

worries and symptoms and keep changing the subject. If this upsets or hurts you because you want them to support you, try telling them. Start perhaps by saying that you do know what is happening and it will help you if you can talk to them about your illness.

Anger

‘Why me of all people?’ ‘And why right now?’

Anger can hide other feelings such as fear or sadness and you may vent your anger on those closest to you. You might feel angry towards the doctors and nurses who are caring for you. If you have a religious belief you may feel angry with your God.

It is easy to see why you may be deeply upset by many aspects of your illness, and there is no need to feel guilty about your angry thoughts or irritable mood. Relatives and friends are not always aware that your anger is really directed at your illness and not against them. If you can, it might be helpful to tell them this at a time when you are not feeling so angry, or if you would find that difficult perhaps you could show them this section of the booklet.

If you are finding it difficult to talk to your family, tell your nurse or doctor he or she may be able to help you.

Blame and guilt

‘If I hadn’t ... this would never have happened.’

Sometimes people blame themselves or others for their illness, or wonder why it should have happened to them. This may be because we often feel better if we know why something has happened. As doctors rarely know exactly what has caused cancer, there is no reason for you to blame yourself.

Don’t bottle up your feelings.

**Don’t bottle
up your
feelings.**

Resentment

‘It’s all right for you, you haven’t got to put up with this.’

Understandably, you may be feeling resentful and miserable because you have cancer while others are well. Similar feelings of resentment may crop up from time to time during the course of your illness and treatment for a variety of reasons. Relatives too can sometimes resent the changes that the patient’s illness makes to their lives.

It is usually helpful to bring these feelings out into the open so that they can be aired and discussed. Bottling up resentment can make everyone feel angry and guilty.

Withdrawal and isolation

‘Please leave me alone.’

There may be times during your illness when you want to be left alone to sort out your thoughts and feelings. This can be hard for your family and friends who want to share this difficult time with you. Let your family know that whilst you do not feel like talking about your illness at the moment, you will talk to them about it when you are ready.

Sometimes depression can stop you wanting to talk. It may be an idea to discuss this with your G.P. who may prescribe a course of anti-depressant drugs. He or she may decide to refer you to a doctor who specialises in managing the emotional problems of cancer patients. It is common for patients with cancer to feel depressed, so there is no need to feel you are not coping if you ask for help.

There is a booklet, *Who can ever understand? Talking about your cancer*, available. If you would like more information call the Cancer Helpline Freefone 1800 200 700 for a copy.

■ *Learning to cope*

After any treatment for cancer it can take a long time to come to terms with your emotions. Not only do you have to cope with the knowledge that you have cancer but also the physical effects of treatment.

Although the treatment for cancer can have some unpleasant side effects, many people do manage to live a normal life during treatment. You will need to take some time off for your treatment as well as time afterwards to recover. Just do as much as you feel like and take plenty of rest. It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling they can give more support.

■ *What if you are a relative or friend?*

You may find it hard to know what to say when someone close to you is diagnosed with cancer. It may seem best to pretend that everything is fine and carry on as normal. You may not want to add to the person's worry by seeming afraid or by saying the wrong thing.

Sadly, denying strong feelings like this can make it even harder to talk openly together and can lead to the patient feeling very

You can help by listening carefully to what the person with cancer wants to say about his or her illness.

lonely. You can help by listening carefully to what the person with cancer wants to say about his or her illness. Don't say too much – let them do most of the talking.

You may not think you are doing much by just listening. In fact you are being very helpful. You are encouraging the person to share their feelings and showing them that they are worth listening to. Listening also helps you to understand their concerns.

Above all let them know that you are there when they want to talk or need help.

A booklet, *Lost for words – How to talk to someone with cancer*, written for relatives and friends of people with cancer is available. Call the Cancer Helpline Freefone 1800 200 700 for a copy, you may find this booklet helpful.

■ *Talking to children*

How much you tell children will depend on how old they are. Very young children don't understand illness and need a very simple account as to why their parent or friend has had to go to hospital. Slightly older children will need to be told more. A simple story talking about good cells and bad cells may help. Every child needs to know what will happen while you are in hospital. Who will look after them, prepare their meals and take them to school? They also need to be reassured that your illness is not their fault.

Whether they show it or not, children feel they may somehow be to blame and may feel guilty. Most children over ten years of age can grasp fairly detailed explanations of what is wrong.

An open honest approach is usually the best way for all children.

Adolescents can understand much more. They may have special needs in learning to cope with the situation. They may be torn between concern for you and trying to become more independent. An open honest approach is usually the best way for all children. You may find that your children rebel or turn quiet. This may be their way of making known their feelings. Even very young children can sense when something is wrong so don't keep them in the dark. They may think that things are much worse than they are.

There is a booklet, *What do I tell the children? – A guide for the parent with cancer*, available. If you would like more information call the Cancer Helpline Freefone 1800 200 700.



■ *What you can do*

Many people feel helpless when they are first told they have cancer. They think there is nothing they can do other than hand themselves over to the doctors and hospital. This is not true. There are many things that you can do at this time.

If you and your family understand your illness and its treatment you will be better able to cope.

- Always ask for information that is personal to you from your own doctors.
- Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor. Write down the answers if you want.
- Let your doctor know if you have any problems or worrying side effects. He or she can decide what to do to help you. If you say nothing a small problem can become more serious.
- At times you may not be able to do the things you used to take for granted. As you begin to feel better you can set yourself some simple goals and slowly build your confidence again. Take one step at a time. Many people talk about "fighting their cancer." This can help some people feel more in control of what is happening to them. You can do this by becoming involved in your illness.
- Try to eat as well as you can. Eat little and often using lots of different types of foods with plenty of fresh fruit and vegetables
- Think about joining a 'support group'. These groups allow you to talk through your feelings with others who have been diagnosed and treated for cancer.
- Join a relaxation class or listen to relaxation tapes.

■ Take some regular exercise. Take it easy at first, building up the amount you do, as you feel stronger.

■ Some people find it helpful to talk to a counsellor.

If the idea of changing your diet or taking exercise does not appeal to you, don't do it. Just do whatever suits you. Some people find pleasure in keeping to their normal routine as much as possible. Others prefer to take a holiday or spend more time on a hobby.

■ *Life after treatment*

There are a number of precautions you can take to protect your skin.

Many patients are delighted when the treatment ends and they are told that they no longer have cancer. However, after treatment for melanoma it is most important that you do not expose your skin to strong sunlight. You may have an increased risk of developing melanoma, either at the same or a different place on your body. There are a number of precautions you can take to protect your skin.

Self-examination

The best way to detect a melanoma early is to inspect your skin at regular intervals. Your doctor will show you how to examine your skin and tell you what to look out for. If you examine your skin regularly you will become familiar with your moles. You will also notice any change in existing moles or the growth of new moles more quickly. Do a thorough inspection, checking your hands and the soles of your feet as well. Ask a relative or friend to check your back or any areas you cannot see clearly. If you notice something that concerns you go and see your doctor as soon as possible. He or she will decide what to do.

Protecting your skin

After treatment for melanoma it is more important than ever to avoid strong sunlight, particularly at the site of the treated melanoma.

- Stay out of the sun during the hottest part of the day. This is normally between 11 a.m.- 3p.m.
- Wear loose clothing made of cotton or natural fibres that have a close weave and offer more protection against the sun. Cover up your skin with long sleeved tops and wear long trousers. Even on a cloudy day you can still get sunburn.
- Protect your face and neck with a wide-brimmed hat and always wear sunglasses in strong sunlight.
- Use a high skin protection factor (SPF) sunscreen whenever you are exposed to the sun. Follow the instructions on the bottle and reapply frequently, especially after swimming.
- Do not sunbathe. Never allow your skin to burn.
- Do not use sunbeds.

Regular check-ups

As well as taking time to examine your own skin you will have to attend a skin specialist for regular check-ups. Your doctor may recommend that you attend for a check-up every six months or more often. These visits will become less frequent as time goes on. A melanoma that is treated early has a greater chance of being cured. If you are unable to attend for your check-up contact your doctor as soon as possible for another appointment.

A melanoma that is treated early has a greater chance of being cured.

■ *Children and melanoma*

Melanoma and other types of melanoma are rarely seen in children. However, if a child is born with a giant birthmark (naevus) there is a slight risk that it may change and a melanoma develop on it. It is also known that certain skin types burn more easily when exposed to strong sunlight. There appears to be a connection between severe sunburn as a child and the development of melanoma later on in life. Therefore, it makes sense to protect children's skin from an early age. This protection will help reduce the risk of skin damage and developing melanoma.

... it makes sense to protect children's skin from an early age.

All children under six months of age should be kept out of direct sunlight. From the age of six months, they should wear either a total sunblock or a sunscreen with a high protection sun factor when exposed to direct sunlight. These should be reapplied frequently especially if the child is swimming or playing with water. A loose T-shirt and hat should be worn at all times. Children should be kept out of the sun during the hottest part of the day.

Your family

If you have had treatment for melanoma, other members of your family such as your brothers or sisters or children may be at risk of developing melanoma as well.

The level of risk depends on their skin type and if they have a lot of unusual looking moles. If any member of your family is concerned about melanoma they should make an appointment to see a skin specialist. He or she will examine their skin and advise

them on what to do. Whatever their skin type, all the members of your family should practice self-examination and follow the guidelines for protecting their skin. Remember that in most cases, melanoma is preventable. If it does occur, it can be cured if diagnosed and treated early.



■ Who can help?

The most important thing to remember is that there are people ready to help you.

The most important thing to remember is that there are people ready to help you and your family throughout treatment and afterwards. The medical social worker in your hospital can help in many ways. He or she provides support and counselling to the patients and their families and can provide advice on benefits, entitlements and services available when you go home.

Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses provide support to patients and their families from the time of diagnosis and throughout treatment. These people, along with other members of your medical team work together to meet your needs.

When you go home there are a variety of community health services available from your local health centre. These centres are staffed with family doctors, public health nurses (who can visit you at home), welfare officers and home help organisers. All these people can provide advice and support.

You can get more information on the services available either from the medical social worker in the hospital before you go home or at your local health centre.

The Irish Cancer Society Helpline nurses are happy to discuss any concerns you or your family may have, at any stage of your illness. They can give you more information about any of the services outlined above and can also let you know about support services in your area. A useful booklet called the Directory of Cancer Care Services in Ireland, is available free of charge. For a copy, call the Cancer Helpline Freefone 1800 200 700.

■ Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of what these entail are given in the following pages. At the end of this section there are some useful telephone numbers and addresses for further help.

Hospital cover

At present everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €55 a night charge up to a maximum of €550 in any 12 consecutive months. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or A&E department of a public hospital, without being referred there by a GP, you may be charged €55. There is no charge if you are referred by a GP. This charge does not apply if you have a medical card or are admitted to hospital as a result of attending the A&E department first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services, and outpatient services and medical appliances. Every person aged 70 or over has a right to a medical card and no means test is required. It covers the applicant only and not their dependents.

For most people, eligibility for a medical card is dependent on a means test. Financial guidelines are set out each year and these are available from your local Health Service Executive (HSE) office, i.e. the former health board. If your means are above but close to the guidelines, you should apply for a card anyway as a card is granted in some situations. For example, if you have a large amount of medical expenses, you may be granted a medical card. Also you may be eligible for a medical card as an individual because you have a cancer diagnosis. In this case your spouse and children will not be covered if your means are over the limit.

If you do not qualify for a full medical card, you may be eligible for a new type of medical card. This covers visits to the doctor and is being introduced in 2005. This will only cover visits to your doctor and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested. Check with the hospital social worker or your HSE office to see if you are eligible.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependant children pay a maximum of €85 each month to cover the cost of prescribed drugs, medicines and appliances. If you have not already received a DPS card for yourself and your family, you can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your pharmacy. If you opt for egg freezing, the cost of the drugs used in the procedure can be reclaimed through the DPS.

Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland this is available through the VHI, BUPA and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. It is advisable to check the level of cover provided by your insurance company, both for inpatient and outpatient services, before attending hospital.

Benefits and Allowances

Disability benefit

This is a benefit for insured people. Eligibility will depend on your PRSI contributions. You must be under 66 and unfit to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social and Family Affairs, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within seven days of becoming ill and unable to attend work. A delay might result in loss of payment.

Disability allowance

You may qualify for Disability Allowance if you are not eligible for Disability Benefit and not able to work for at least a year. Disability Allowance is a weekly allowance paid to people with a disability who are aged between 16 and 66. You must have a means test and be medically suitable for this allowance. To be medically suitable you should have an illness that has continued or may continue for at least one year. This means that you are unlikely to be able to work for at least a year due to your illness.

Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Invalidity pension

This is a pension paid instead of a Disability Benefit or Allowance, if you are unable to work in the long term. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over age 60 and have a serious illness or incapacity.

Your eligibility for this pension will also depend on your PRSI contributions. You are allowed a free travel pass and certain extra benefits, such as bottled gas, telephone rental, fuel allowance and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Carer's allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. There are a number of benefits with this scheme such as a free travel pass for the carer, free television licence, and home energy allowance. A telephone allowance has been extended to carers giving full-time care. There is also a contribution towards respite care. This is a means-tested allowance.

For more advice, talk to your social worker and/or the Dept of Social and Family Affairs. Application forms are available from

your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211, Ext. 8940 or Dublin (01) 704 3000, Ext. 8940.

Carer's Benefit

If you are employed but wish to care for a sick relative, you may qualify for a Carer's Benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. Under Carer's Leave legislation, you may be entitled to unpaid temporary leave from your employment. You should apply for Carer's Benefit eight weeks before you intend to leave employment so that your eligibility can be assessed prior to leaving your employment.

More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211, Ext. 8787 or Dublin (01) 704 3000, Ext. 8787.

Appliances

For patients who have medical cards most appliances are free of charge. For example, you are entitled to a new hairpiece or wig every six months.

Travel to hospital

Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE offices provide transport services to hospitals for outpatient appointments

and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, people who do not have medical cards may be charged for the service. However, the practice varies between HSE areas and is often dependent on personal circumstances. Charges may be waived in certain cases, e.g. hardship, etc.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements which may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

For social welfare queries contact:

Information Service, Dept of Social and Family Affairs, Áras Mhic Dhiarmada, Store Street, Dublin 1
Tel: 01 874 8444; Leaflet line: 1890 202 325; Email: info@welfare.ie;
Website: www.welfare.ie

In 2004 the functions of the health boards were transferred to the Health Service Executive (HSE). Email: www.hse.ie. If you have queries about any health and social services, contact the HSE office in your area.

HSE Eastern Region [formerly Eastern Regional Health Authority]

Customer Services Department
Dr Steeven's Hospital
Dublin 8
Tel: 01 635 2400
or Freephone 1800 520 520
Email: customerservices@erha.ie
Website: www.erha.ie

HSE Midland Area [formerly Midland Health Board]

Head Office
Arden Road
Tullamore
Co Offaly
Tel: 0506 218 68
Fax: 0506 517 60
Website: www.mhb.ie

HSE Mid Western Area [formerly Mid Western Health Board]

Head Office
31–33 Catherine Street
Limerick
Tel: 061 316 665
Fax: 061 483 250
Website: www.mwhb.ie

HSE North Eastern Area [formerly North Eastern Health Board]

Head Office
Navan Road
Kells
Co Meath
Tel: 046 9280 500
Fax: 046 9241 459
Website: www.nehb.ie

HSE North Western Area [formerly North Western Health Board]

Head Office
Manorhamilton
Co Leitrim
Tel: 071 9820 400 /1850 636 313
Fax: 071 9820 431
Website: www.nwhb.ie

HSE South Eastern Area [formerly South Eastern Health Board]

Head Office
Lacken
Dublin Road
Kilkenny
Tel: 056 7784 100
Fax: 056 7784 388
Website: www.sehb.ie

HSE Southern Area [formerly Southern Health Board]

Head Office
Wilton Road
Cork
Tel: 021 4545 011
Website: www.shb.ie

HSE Western Area [formerly Western Health Board]

Head Office
Merlin Park Regional Hospital
Galway
Tel: 091 751 131
Fax: 091 752 644
Website: www.whb.ie

Information is also available from your local Citizens Advice Centre. A list of these centres is available from:

Comhairle (formerly the National Social Services Board)

7th Floor

Hume House

Ballsbridge

Dublin 4

Tel: 01 605 9000

Citizen Information: 1890 777 121

Email: comhairle@comhairle.ie

Website: www.comhairle.ie

There are also some booklets available that may help you. These include:

Directory of Cancer Care Services in Ireland published by the Irish Cancer Society. For a free copy call National Cancer Helpline 1800 200 700. Email: helpline@irishcancer.ie

Information Guide to Health Services published by the Dept of Health and Children. Copies are available from your local HSE office. Tel: 01 671 4711 for local HSE numbers.

Guide to Social Welfare Services published by the Dept of Social and Family Affairs. Copies available from the Dept of Social and Family Affairs. Tel: 01 874 8444. Email: info@welfare.ie.
Website: www.welfare.ie

Entitlements for People with Disabilities published by Comhairle. Tel: 01 605 9000. Email: comhairle@comhairle.ie

■ *Irish Cancer Society Services*

The Irish Cancer Society funds a range of cancer support services that provide care and support for people with cancer at home and in hospital.

Homecare nurses

Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. These nurses work with GPs and public health nurses to form homecare teams bringing care and support, free of charge, to patients in their own homes. Based in local hospitals, health centres and hospices, they can be contacted through your GP or public health nurse.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to seven nights to families who are caring for a seriously ill person at home. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse.

Oncology liaison nurses

The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to the patient and his or her family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

National Cancer Helpline

The National Cancer Helpline gives confidential information, support and guidance to people concerned about cancer. This is a freefone service. The specially trained nurses who staff the Helpline have access to the most up-to-date facts on cancer-related issues, using a computerised directory and library of resources. The nurses can provide information to anyone enquiring about treatment, counselling and other support services. They can also help you to make contact with the various support groups that are available. The Helpline 1800 200 700 operates weekdays from 9 am to 5 pm.

Counselling

Coping with a cancer diagnosis can be very stressful. Patients and their families sometimes find it difficult to come to terms with the illness. Many people feel that they cannot talk to a close friend or relative. Counselling can provide emotional support in a safe and confidential environment. Call the Cancer Helpline to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards.

Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Irish Cancer Society.

Patient grants

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial assistance to patients in need. Requests for this kind of help should be directed through your social worker, GP or public health nurse. If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.

■ Useful organisations

Irish Cancer Society

43–45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Tel: 01 231 0500
Fax: 01 231 0555
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Comhairle (formerly National
Social Services Board)
7th Floor, Hume House
Ballsbridge
Dublin 4
Tel: 01 605 9000
Email: comhairle@comhairle.ie

**Dept of Social and Family
Affairs** – Information Service
Áras Mhic Dhiarmada
Store Street
Dublin 1
Tel: 01 874 8444
Email: info@welfare.ie
Website: www.welfare.ie

HARI Unit (Human Assisted
Reproduction Ireland)
Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732

Health Promotion Unit
Dept of Health and Children
Hawkins House
Hawkins Street
Dublin 2
Tel: 01 635 4000
Website: www.healthpromotion.ie

Health insurers

BUPA Ireland
Mill Island
Fermoy
Co Cork
Locall: 1890 70 08 90
Fax: 025 42122
Email: choices@bupa.ie
Website: www.bupa.ie

Vivas Health

Paramount Court
Corrig Road
Sandyford
Dublin 18
Tel: 1850 717 717
Email: support@vivashealth.ie
Website: www.vivashealth.ie

Voluntary Health Insurance (VHI)

VHI House
Lower Abbey Street
Dublin 1
Tel: 01 872 4499
Email: info@vhi.ie
Website: www.vhi.ie

Support groups & support centres

ARC Cancer Support Centre
ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email:
info@arccancersupport.ie
Website: www.arccancersupport.ie

Bray Cancer Support & Information Centre

36B Main Street
Bray
Co Wicklow
Tel: 286 6966
Email: bcsc@iol.ie
Website: www.braycancersupport.ie

Cancer Information & Support Centre

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 482615

Cancer Plus

[support group for
parents of children with cancer]
Irish Cancer Society
43–45 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Fax: 01 231 0555
Email: support@irishcancer.ie

CanTeen Ireland
Young Peoples' Cancer
Support Group
c/o Carmichael Centre
Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: canteen@oceanfree.net

Cork ARC Cancer Support House
Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 434 6688

Donegal Cancer Support Group
Clar
Co Donegal
Tel: 074 974 0837

The Gary Kelly Support Centre
Georges Street
Drogheda
Co Louth
Tel: 041 980 5100
Fax: 041 980 5101
Email: info@garykellycentre.org
Website: www.garykellycentre.org

Greystones Cancer Support
La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601

HOPE
Enniscorthy Cancer Support &
Information Centre
6 Church Street
Enniscorthy
Co Wexford
Tel: 054 38555

The LARCC Retreat Centre
Ballinalack
Mullingar
Co Westmeath
Tel: 044 71971
Email: info@larcc.ie
Website: www.larcc.ie

Lios Aoibhinn Cancer Support Centre
St Vincent's University Hospital
Herbert House
St Anthony's
Herbert Avenue
Dublin 4
Tel: 01 277 3545

Men Against Cancer (MAC)
43-45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Mayo Cancer Support Association
Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407

Slánú Cancer Help Centre
Birchall
Oughterard
Co Galway
Tel: 091 550050
Email: info@slanu.ie
Website: www.slanu.ie

Sligo Cancer Support Centre
2A Wine Street
Sligo
Tel: 071 70399
Email: scsg@tinet.ie

South East Cancer Foundation
7 Sealy Close
Earlscourt
Waterford
Tel: 051 590881

The Tuam Cancer Care Centre
30 Temple Jarlath Court
High Street
Tuam
Co Galway
Tel: 093 28522
Email: info@tuamcancercare.ie
Website: www.tuamcancercare.ie

Turning Point – Positive Health Centre
23 Crofton Road
Dun Laoghaire
Co Dublin
Tel: 01 280 7888
Email: turningpoint@eircom.net
Website: www.turningpoint.ie

Useful contacts outside Ireland

American Cancer Society
1599 Clifton Road NE
Atlanta, GA 30329-4251
Website: www.cancer.org

CancerBACUP

3 Bath Place
Rivington Street
London EC2A 3JR
Tel: +44 207 696 9003
Helpline: +44 207 7392280
Website: www.cancerbacup.org.uk

Cancer Link UK

11–21 Northdown Street
London, N1 9BN
Tel: +44 171 833 2818
Fax: +44 171 8334963
Website: www.cancerlink.org

Macmillan CancerLine

Macmillan Cancer Relief
89 Albert Embankment
London SE1 7UQ
Tel: +44 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

MARCS Line

Dermatology Treatment
Centre, Level 3
Salisbury District Hospital
Salisbury
Wiltshire SP2 8BJ
Tel: 0044 172 241 5071
Email: marcsline@wessexcancer.org
Website: www.wessexcancer.org

National Cancer Institute (US)

Website: www.nci.nih.gov

The Ulster Cancer Foundation

40–42 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 906 63281
Website: www.ulstercancer.co.uk

University of Pennsylvania

Cancer Center
Website: www.oncolink.com

■ *Helpful books*

Cancer at Your Fingertips (2nd edn)
Val Speechley
& Maxine Rosenfeld
Class Publishing, 2001
ISBN 1-85959-036-5

Cancer Explained
Prof Fred Stephens
Newleaf, 1997
ISBN 0-71712-793-1

*Cancer Positive: The Role of the
Mind in Tackling Cancers*
Dr James Colthurst
Michael O'Mara Books Ltd, 2003
ISBN 1-85479-860-X

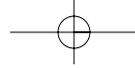
*Cancer: What Every Patient Needs
to Know*
Jeffrey Tobias
Bloomsbury, 1999
ISBN 0-74754-565-0

*Challenging Cancer:
Fighting Back, Taking Control,
Finding Options*, (2nd edn)
Dr Maurice Slevin
& Nira Kfir
Class Publishing, 2002
ISBN 1-85959-068-3

Taking Control of Cancer
Beverley van der Molen
Class Publishing, 2003
ISBN 1-85959-091-8

*The Bristol Approach
to Living with Cancer*
Helen Cooke
Robinson, 2003
ISBN 1-84119-680-0

*The Key Model –
A New Strategy for Cancer
Recovery*
Dr Sean Collins
& Rhoda Draper
Ardagh Clinic, 2004
ISBN 0-95214-445-X



■ *Frequently asked questions*

Here is a list of questions people often want to ask. There is also some space for you to write down your own questions if you wish. Do ask questions – it is always better to ask than to worry.

- What is melanoma?
- What type of treatment do I need?
- How successful is this treatment for my cancer?
- Are there other treatment options? Why is this one best for me?
- What side-effects or after-effects will I have?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- Is there anything I can do to help myself during treatment?
- Do I need to use contraception during my treatment? What will happen if I, or my partner, get pregnant?
- Should I eat special foods?
- What can I do to reduce the risk of getting another melanoma?
- Do my family need to be checked for melanoma? If so, how can this be organised?

■ *Your own questions*

1 _____

Answer _____

2 _____

Answer _____

3 _____

Answer _____

4 _____

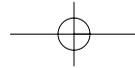
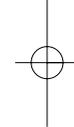
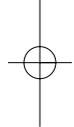
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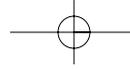
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Answer _____

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Answer _____

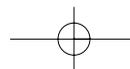
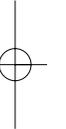




■ *Notes*



■ *Notes*



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We hope that this booklet has been of help to you. If you have any suggestions as to how it could be improved, we would be delighted to hear from you. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If, after reading this booklet or at any time in the future, you feel you would like more information or someone to talk to, please phone our Cancer Helpline Nurses on Freefone 1800 200 700.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us.

Irish Cancer Society, 43–45 Northumberland Road, Dublin 4.

Tel: 01 231 0500. Email: info@irishcancer.ie