

Understanding

Melanoma

Caring for people with cancer

Understanding

Melanoma

This booklet has been written to help you understand more about melanoma. It has been prepared and checked by dermatologists, surgeons, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and how it may affect you.

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



Specialist nurse	Tel:
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Family doctor (GP)	Tel:
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Dermatologist	Tel:
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Plastic surgeon	Tel:
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Medical oncologist	Tel:
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Medical social worker	Tel:
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Radiation oncologist	Tel:
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Radiation therapist	Tel:
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Emergency number	Tel:
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If you like, you can also add:

Your name

Address

This booklet has been produced by 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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Introduction

This booklet has been written to help you understand more about a type of skin cancer called melanoma. This type of skin cancer usually affects the melanin cells in your skin. It is also known as malignant melanoma. If diagnosed early, many melanomas can be cured successfully.

The booklet is divided into four parts:

- **About melanoma** gives an introduction to melanoma, including causes, symptoms and diagnosis.
- **Treatment and side-effects** looks at the different treatments used for melanoma and possible side-effects.
- **Coping and emotions** discusses your feelings and the emotional effects of having melanoma.
- **Support resources** gives information on further sources of help and support. This includes helpful organisations, books, support groups and websites. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care, as the best choice for you will depend on your particular cancer and your individual circumstances.

>>> Reading this booklet

Remember you do not need to know everything about melanoma straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section.



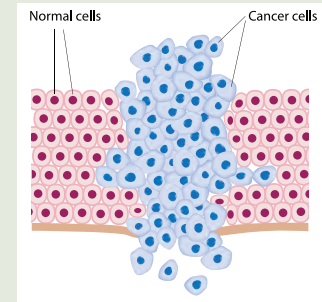
If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freefone National Cancer Helpline on 1800 200 700. It is open from Monday to Thursday 9am–7pm and Friday 9am–5pm. You can also visit a Daffodil Centre. See page 60 for more about Daffodil Centres.

About melanoma

>>> What is cancer?

Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer, breast cancer or leukaemia. All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

Tumours can be either benign or malignant. Benign tumours do not spread to other parts of your body but malignant tumours do. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body. This is called a metastasis or secondary tumour.



Cancer cells

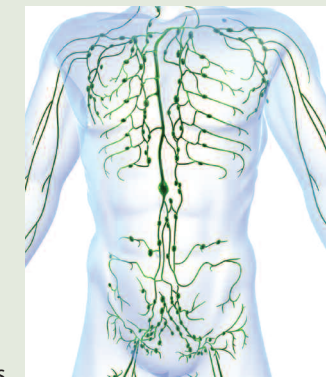
What is the lymphatic system?

The lymphatic system is made up of groups of lymph nodes throughout the body.

Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels.

These lymph vessels are tiny tubes, which usually lie just under the skin. The lymph vessels transport lymph fluid, which carries extra fluid and waste from body tissues.

Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.



Lymphatic system

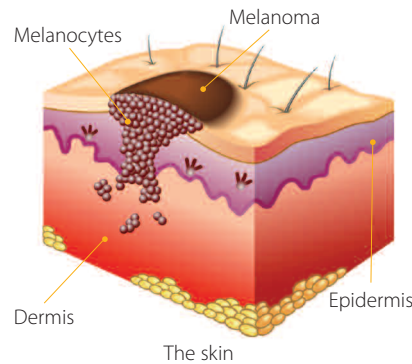


To sum up

- Cancer is a disease of the cells of your body.
- With cancer, the cells do not behave as normal. They keep on growing even when there is no need.
- If a tumour is malignant, cells can break away and be carried by your bloodstream or lymph vessels somewhere else. This is called a metastasis or secondary tumour.

Your skin

Your skin is the largest organ in your body. It has two main layers, the epidermis and the dermis. The outer layer is called the epidermis and has cells called melanocytes at its base. These cells make a pigment called melanin, which gives your skin its colour. Melanin protects your skin against damage from the ultraviolet (UV) rays in sunlight. The lighter your skin colour, the more easily it can be damaged by sunlight.



The dermis is the inner or deeper layer of your skin. It contains blood and lymph vessels, hair follicles and glands.

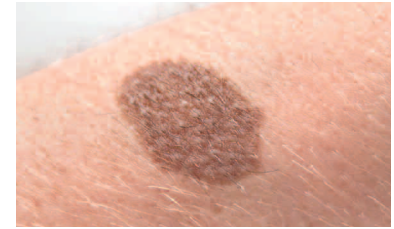
As well as making melanin, your skin has other functions. For example:

- It protects your body from injury and infection.
- It helps to control your body temperature.
- It removes waste products like salt and other minerals from your body.

What is a mole?

A mole is a group of melanocytes that form a mark on your skin. There are several different types. The most common ones are birthmarks or childhood moles.

- **Birthmarks:** Birthmarks are very common. They are small brown or black spots that can be found on a child's skin at birth or soon afterwards. Most birthmarks get slightly bigger as a child gets older. They may also become darker in colour. Most birthmarks are harmless.



Birthmark

- **Ordinary moles:** These are small evenly coloured brown, tan or black spots found on your skin. They can be either flat or raised and also round or oval. In size, they are usually less than the top end of a pencil. They appear on the skin during childhood. Most people have about 20–40 small brown or slightly raised moles. Like birthmarks, they are usually harmless and should be left alone.

Moles usually stay the same size, shape and colour for many years. As you get older, they may change slightly, becoming darker in colour and raised above the surface of your skin. They often fade away in older people.



Mole

If a birthmark or mole gets darker, larger, lumpy or starts to bleed, visit your family doctor (GP). See page 11 for changes to birthmarks or moles.



What is melanoma?

Melanoma is a cancer in the cells that make 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 your body. For example, your eye, mouth, under your fingernails or toenails, or in your bowel.

If melanoma is diagnosed and treated early, there is a very good chance of a cure. But it can spread to other parts of your body or within the skin itself. Melanoma is also known as malignant melanoma.

>>> Melanoma is a cancer in the cells that make melanin.

How common is melanoma?

Melanoma is one of the most common cancers among people aged 15–44. The number of people in Ireland being diagnosed with melanoma has risen dramatically in the past few years. Each year around 880 cases of melanoma are diagnosed in Ireland. At present more women than men are affected.

What are the types of melanoma?

There are several types of melanoma.

- **Superficial spreading melanoma:** This is the most common type. It grows along the surface of your skin, often on your legs or chest and back. It may grow out of a mole that has suddenly changed.
- **Nodular melanoma:** This is the second most common type. It is more common in men. It grows quite quickly down into the deeper layers of your skin. It may occur in normal skin that is not exposed to the sun very often. It has a raised area on the skin and may be brown or black in colour.
- **Lentigo maligna melanoma:** This is usually found in older people and often on the face. It begins as a small, brown freckle or stain and gradually spreads to form a bumpy surface. It can grow slowly over many years.

- **Acral melanoma:** This is usually found in the palms of your hands, soles of your feet or around your toenails. It is more common in dark-skinned people.

Melanoma in other parts of the body

Melanoma is usually found on the skin. It can develop in other parts of the body, but this is rare. Melanoma can happen in the eye or in tissues that line areas inside the body. For example, the anus or rectum (anorectal melanoma), nose, mouth or lungs. These types of melanoma are not discussed in detail in this booklet. For more information, contact the National Cancer Helpline 1800 200 700 or visit a Daffodil Centre.

>>>

Melanoma of the eye



Melanoma can sometimes develop in your eye, but it is rare. It develops in the lining of the eyeball called the uvea. Your doctor might call it uveal melanoma or ocular 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, your eye specialist can find the tumour by looking at the back of your eyeball with a special instrument.

Treatment

The aim of treatment is to remove the cancer and save as much of your 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 check-ups. That way, the tumour can be watched closely.

What are the risk factors for melanoma?

The exact cause of melanoma is unknown. Research continues to study possible causes. But there are certain things called risk factors that can increase your chance of getting the disease. These include:

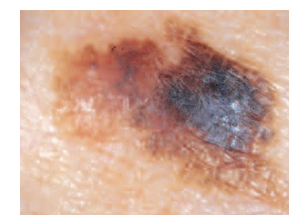
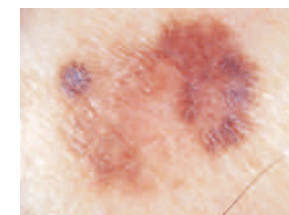
- **UV rays:** Exposure to ultraviolet (UV) rays from sunlight or tanning lamps and sun beds greatly increases your risk of developing melanoma. Being outside can expose your skin to the sun's harmful UVA and UVB rays, even on cool or cloudy days.
- **Sun beds:** People who have used a sunbed, even just once, have a 20% increased risk of melanoma. Using sunbeds from a young age increases your risk even more.
- **Number and type of moles:** Having a large number of moles or moles that are unusual can increase your risk of melanoma.
- **Age:** Melanoma affects all age groups but is most common between the ages of 30 and 60 years. The risk of developing it increases with age.
- **Skin type and eye colouring:** You are more at risk if you are fair skinned with fair or red hair and blue, green or grey eyes. But dark skin too can sometimes get melanoma.
- **Lifetime exposure to sunlight:** Being exposed to UV rays over your lifetime or severe sunburn or blistering as a child or adolescent may increase your risk of developing melanoma later in life.
- **Family history of melanoma or skin cancer:** Your risk is increased if you or a family member have a history of skin cancer.
- **Weakened immune system:** If you have a weakened immune system, your risk of melanoma is greater. This can happen if you have had an organ transplant or have HIV/AIDS.
- **Genetic skin disorders:** Your risk is greater if you have a genetic condition that makes your skin more sensitive to sunlight. For example, xeroderma pigmentosum.

Remember melanoma is not infectious and cannot be passed on to other people.

What are the signs of melanoma?

It is important to notice any change in the size, shape or colour of a mole. Most melanomas can be seen on the surface of the skin. The main signs of melanoma may include one or more of the following:

- A mole that suddenly gets bigger or you find a new one on your skin in adult life.
- The mole develops a ragged or uneven outline. The shape is irregular with one half unlike the other.
- The mole looks different to all your other moles.
- The mole has a mixture of different shades. For example, many shades of tan, brown or black, sometimes white, red or blue.
- The mole is bigger than the top of a pencil.
- The mole looks red or inflamed around the edges.
- The mole is bleeding, oozing or crusting.
- The mole starts to feel different. For example, slightly itchy or painful.



If you have any of the above signs, get 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. It is normal for moles to slowly enlarge and develop during childhood and teenage years.

»»» It is important to notice any change in the size, shape or colour of a mole



To sum up

- Melanoma is a cancer in the cells that make melanin.
- The exact cause of melanoma is unknown. The risk of developing it increases with exposure to UV rays from sunlight or sunbeds, age, fair skin, moles, and a family history of melanoma.
- The signs of melanoma are a change in the size, shape or colour of a mole, if it looks red and inflamed, bleeds, oozes, crusts, or feels itchy or painful.
- Melanoma can happen in other parts of the body, but this is rare.

How is melanoma diagnosed?

First visit your family doctor (GP) who will examine your skin carefully. If he or she suspects a melanoma, they should refer you immediately to a skin specialist, such as a dermatologist or plastic surgeon. You should be seen without delay.

The tests at the hospital may include:

- Skin exam
- Excision biopsy

Skin exam

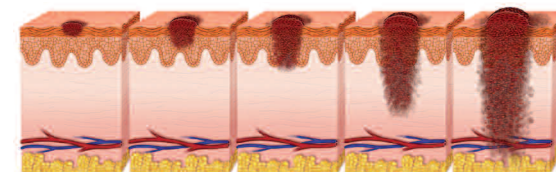
In most cases, the dermatologist can tell if the mole is harmless or not just by looking at your skin. He or she can also use a special magnifying glass called a dermatoscope to examine the area closely. The area can be photographed as well. Your dermatologist will also ask you about any family history of melanoma.

Excision biopsy

A biopsy means taking a sample of cells and looking at them under a microscope. But with a mole a sample is never just taken. Instead, the entire mole is removed by your dermatologist or plastic surgeon. This is called an excision biopsy and it can diagnose melanoma.

The mole is usually removed under local anaesthetic. A small cut is made through your skin and the mole removed. At least 2–5 mm of normal-looking skin around the affected area is removed as well. This is to make sure there are no possible melanoma cells left behind. The excision biopsy is quick and only takes about 5–10 minutes. It normally causes very little pain. The local anaesthetic used to numb your skin can sting a little when first given. Afterwards the mole tissue is examined in the laboratory by a doctor called a pathologist.

The pathologist will write a report on how the cells look under the microscope. The pathologist will measure the thickness (depth) of the melanoma to see if the cancer cells have spread into the deeper layers of your skin. This is called the Breslow thickness. If the depth of the melanoma is less than 1mm, it is called a thin melanoma and you have an excellent chance of a complete cure. Most people have melanomas that are 1mm thick or less. If it is thicker than 1 mm, there is a chance it could have spread or might come back in the future.



The pathologist will see if there are signs that cancer cells have spread to the area around the mole. He or she will also check how fast the cells are dividing (mitotic rate). If the cells are dividing fast there is a greater chance of the cancer spreading.

The biopsy results will help your doctors to decide if you need further tests or treatment. The waiting time for the result of the excision biopsy can vary. It might take a few weeks to get the results.

➤➤➤ Most people do not need further tests.

Further tests

Often an excision biopsy is the only treatment you need and the biopsy results show that any cancer has been removed. If the excision biopsy shows that the cancer has or might spread beyond your skin surface, your doctor may need to do other tests to find out more about the extent or stage of the cancer. This can help your doctor to decide on the right treatment for you. See page 17 for more about staging melanoma.

The further tests may include:

- Sentinel node biopsy
- CT scan
- PET scan
- Ultrasound scan of your liver and abdomen
- MRI scan
- Bone scan

Sentinel lymph node biopsy: Cancer cells can sometimes spread to the lymph nodes close to the melanoma site. This is unlikely to happen if the melanoma is less than 1mm thick. If the melanoma cells go deeper than 1 mm into your skin, your doctor may do a test during surgery to find out if the melanoma has spread to your lymph nodes. This test is called a sentinel node biopsy.

In this test, a tiny amount of radioactive liquid or dye is injected into the scar site of the melanoma. This liquid will travel to the lymph nodes. The lymph nodes are then scanned to see which ones have taken up the liquid. The first node to take up the liquid is called the sentinel node. This node is then removed and sent to the laboratory to be examined.

If the sentinel node has melanoma cells, all the lymph glands in the area are removed. For more details, see page 25. 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 needed.

A sentinel node biopsy is straightforward. If any problems occur, they tend to be minor. Some people get infections at the biopsy site and may need antibiotics after the test. For others, fluid or blood might collect in the biopsy site and may need to be drained off.

These problems usually clear up within a few weeks of the test. There is a very small chance of lymphoedema (swelling in the area) after the biopsy. Overall, the test is safe and there is no danger from the radioactive liquid.

CT scan: This is a special type of X-ray that gives a detailed picture of the tissues inside your body. The test is usually done as an outpatient. The scan itself is painless and lasts about 30 minutes. You might need to fast from midnight or 4 hours before the test. You might also be given an injection or a



CT scan

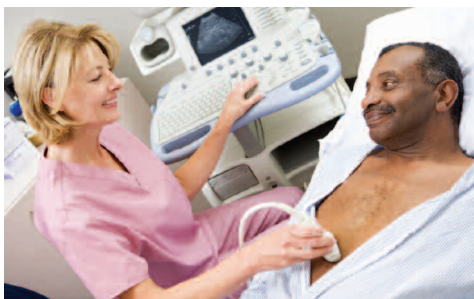
special drink to help show up certain parts of your body on the scan. Preparation for a CT scan can vary but your doctor or nurse will tell you what to do.

PET scan: PET stands for positron emission tomography. This scan can give your doctor more information about melanoma and if it is found elsewhere in your body. PET uses a low dose of radioactive sugar to measure the activity in your cells. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are found.

The sugar is first injected into your arm and travels to all the cells in your body. After an hour, the scan is taken and can show on a computer screen if the cancer has spread to other tissues and organs. Before the test, you may have to fast for a few hours. PET is safe to use and there are no side-effects.

Sometimes PET can be used together with a CT scan to give your doctor more information.

Ultrasound scan of your liver and abdomen: This scan uses sound waves to look at the tissues inside your body. In this case, your liver and tummy (abdomen). Once you are lying on your back, some gel is spread on your tummy. A small device like a microphone is then passed over your tummy and takes pictures that can be seen on a screen. It can show any abnormal changes in your liver or other organs in your tummy. The test does not hurt and only last about 10 minutes.



Liver ultrasound

MRI scan: This scan uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but can be very noisy. But you will be given earplugs to wear during it. You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device like a pacemaker or metal piece in your body, you may not be suitable for the test.

Bone scan: Bone scans are very sensitive and can find cancer cells before they show up on X-ray. For this test a very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken of all the bones in your body. 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 3 hours before the scan can be taken. You might like to bring 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 safe. The radioactivity disappears from your body within a few hours.

Waiting for results

It may take some time for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over

with the specialist nurse or with a relative or close friend. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre and speak to one of our specially trained nurses.



To sum up

The following tests are used to diagnose melanoma:

- Skin exam
- Excision biopsy

The following tests might sometimes be done:

- Sentinel node biopsy
- Scans – CT, PET, MRI, ultrasound or bone scans

What are the stages of melanoma?

The excision biopsy and further tests like a sentinel node biopsy and scans like ultrasound, CT, MRI and PET can help to stage melanoma. Staging means finding out the size of the tumour, how deeply it has grown into the skin and if it has spread to other parts of your body. Different treatments are used depending on the stage of your melanoma. Staging helps your doctor to decide the best treatment for you.

With melanoma, staging looks at:

- The thickness (depth) of the tumour (see page 13)
- Whether the tumour has broken the skin. This is called ulceration.
- Whether the tumour has spread to the lymph nodes.
- Whether the tumour has spread to other parts of the body. This is called metastasis.

The stages of melanoma can be described as:

- **Melanoma in situ (Stage 0):** This is the very earliest stage of melanoma. The melanoma cells are only in the very top layer of the skin (epidermis). Melanoma in situ does not usually spread to other parts of the body.
- **Early stage melanoma (Stage 1-2):** The melanoma cells are found in the top layer of your skin only. The melanoma has not spread to lymph nodes or other organs.

- **Medium stage or locally advanced (Stage 3):** The melanoma cells have grown in size, are found in the deeper layers of your skin and may have spread to nearby lymph nodes and other tissues.
- **Advanced melanoma (Stage 4):** The cancer has spread to distant parts of your body like your lung, liver or brain. This is also called metastatic melanoma.

»»» Staging is very important as it allows your doctor to decide the best treatment for you.

Your doctor will use a more detailed staging system to describe the exact size and spread of your melanoma. Staging is often described using numbers 1-4 and letters A-C. It can sometimes be a bit confusing, so ask your doctor or specialist nurse to explain if you have any questions.

Stage 1A: The melanoma is less than 1mm thick. The covering layer of skin over the tumour is not broken – it is not ulcerated.

Stage 1B: The melanoma is less than 1mm thick and the skin is broken (ulcerated). Or it is between 1 and 2mm and is not ulcerated.

Stage 2A: The melanoma is between 1 and 2 mm thick and is ulcerated. Or it is between 2 and 4mm and is not ulcerated.

Stage 2B: The melanoma is between 2 and 4mm thick and is ulcerated. Or it is thicker than 4mm and is not ulcerated.

Stage 2C: The melanoma is thicker than 4mm and is ulcerated.

Stage 3A: The melanoma has spread to 1 to 3 lymph nodes near the original tumour. The nodes are not enlarged and the melanoma can only be seen with a microscope. The melanoma can be of any thickness, but it is not ulcerated.

Stage 3B: The melanoma can be of any thickness and is ulcerated. It has spread to 1 to 3 lymph nodes near the original tumour. The nodes can be enlarged or not enlarged.

OR

The melanoma can be of any thickness, but it is not ulcerated. The melanoma has spread to skin or lymph vessels around the original tumour. Nearby lymph nodes do not contain melanoma.

Stage 3C describes one of the following:

- The melanoma has spread to 1 to 3 lymph nodes near the original tumour. The nodes are enlarged. The melanoma can be of any thickness and is ulcerated.
- The melanoma has spread to skin or lymph vessels near the original tumour. The lymph nodes do not contain melanoma. The melanoma can be of any thickness and is ulcerated.
- The melanoma has spread to 4 or more nearby lymph nodes, or to nearby lymph nodes that are clumped together. The melanoma can be of any thickness and may or may not be ulcerated.
- The melanoma has spread to skin or lymph vessels around the original tumour and to nearby lymph nodes. The nodes are enlarged because of the melanoma.

Stage 4: The melanoma has spread to other areas of the body, such as the lung, liver or brain.



To sum up

- Staging means finding out the size of the tumour and if it has spread to other parts of your body.
- The results of your excision biopsy will help your doctors to decide whether you need further staging tests done.
- Most people with early stage disease do not need further tests.
- Further tests like scans may be used to stage the cancer.



Treatment and side-effects

How is early stage melanoma treated?

Excision surgery

Surgery is the main treatment for early stage melanoma and can usually cure it. Excision surgery removes the entire mole. It is called wide local excision when the melanoma and an area around it are removed.

The surgery is normally done under local anaesthetic in the day surgery unit. A team of doctors, called the multidisciplinary team (MDT), will discuss your case and see if you need more treatment or not. If the melanoma did not spread too deeply below your skin surface, you may need no further treatment.

What follow-up do I need?

Melanoma can come back again (recur). After having melanoma you are more at risk of developing a second melanoma in the same place or elsewhere on your body. For this reason, you must visit your doctor regularly to have your skin examined. This is called follow-up. Your doctor may want to see you quite often at first but the visits will decrease over time. They will continue for at least 5 years.

At these visits your 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 yourself (see page 36). Your doctor will also show you how to do this. If you develop a new melanoma, it is important that it is diagnosed and removed quickly. Early diagnosis of melanoma improves your chance of successful treatment.

If you are between check-ups and have a problem that concerns you, let your doctor know as soon as possible.

It is also very important to protect your skin from UV rays. See the SunSmart code on page 38 for details.

How is locally advanced or advanced melanoma treated?

Melanoma that is locally advanced or advanced can also be treated. The main treatment is surgery.

Locally advanced: Sometimes it is not possible to remove all the melanoma during an excision biopsy. Your doctor may decide to give you more treatment even if the melanoma is found in only one section of skin. There may be a high risk that it may return, depending on its size and thickness.

Advanced: If the melanoma has spread to other parts of your body, you will need more treatment. Treatment will depend on the type and size of melanoma, where it is found and if any organs are affected. You may also be offered new drugs or a combination of drugs as part of a clinical trial.

Treatments include:

Surgery: Surgery can remove the mole (excision surgery) or a larger area (wide local excision) to make sure no melanoma cells are left behind. If melanoma is found in your lymph nodes, these will be removed under general anaesthetic. See page 25 for more about surgery.

Biological (targeted) therapies: These treatments can help to target and destroy cancer cells or stop them from growing. Or they can help your body's immune system to attack cancer cells. See page 27 for more details.

Radiotherapy: Radiotherapy uses high-energy rays to destroy cancer cells. It may be used if your brain or spinal cord is affected or to relieve pain. See page 30 for more details.

Chemotherapy: Chemotherapy uses drugs to control cancer. It is used less than surgery and biological therapies in treating melanoma. See page 29 for more details.

>>> Your doctor will discuss your treatment options with you.

Local recurrence

Occasionally melanoma comes back close to the original melanoma site. This is called local recurrence.

Surgery is the main treatment for a melanoma that comes back in the same area. Other treatments are laser therapy, radiotherapy or isolated limb perfusion (ILP).

For more information on treatments for recurrent melanoma talk to a specialist nurse by calling the National Cancer Helpline on 1800 700 200 or visiting a Daffodil Centre.

Deciding on treatment

Multidisciplinary team meeting: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. They will meet to discuss your test results and decide your treatment plan.

Treatment: Your doctor and nurse will explain your treatment options to you. Do ask as many questions as you like, no matter how small or trivial you think they are. You could use the fill-in page at the back of this booklet for your questions and answers.

Time to think: When faced with a serious illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about your treatment, if you are unsure when it is first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor will refer you to another specialist for a second opinion if you feel this would be helpful.

Accepting treatment: You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse treatment, let your doctor or nurse know your concerns first. You can also speak to a specialist nurse by visiting a Daffodil Centre or by calling the National Cancer Helpline on 1800 200 700. The important thing is that you are fully informed of the benefits and risks.

Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once.

Individual treatment

You may notice that other people with melanoma are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Do not be afraid to ask your doctor about your treatment.



To sum up

- Most melanomas caught early can be treated successfully by surgery.
- Other treatments include biological therapies, radiotherapy and chemotherapy.
- A team of specialists (multidisciplinary team) will decide which treatment is best for you.

Surgery

The aim of surgery is to remove the melanoma and the area close to it. It is called wide local excision when the melanoma and an area around it and underneath it are removed so no melanoma cells are left behind. The area of healthy tissue removed can vary. For example, it can be 1–4 cm of tissue, depending on the size of the melanoma.

This surgery is normally done under local anaesthetic in the day surgery unit. Most melanomas are cured by surgery.

Skin grafts

Sometimes when a wider area of skin is removed the surgeon may need to do a skin graft. A graft means that layers of skin are taken from another part of your body and placed onto the wound. The skin can be taken from your thigh or upper arm. This is called the donor site. The thickness of the skin taken depends on the depth of the area to be covered. Small skin grafts can often be done as day surgery, so you can go home the same day.

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 donor site is also checked and dressed regularly. You may feel sore for a few days after the surgery but you will be given painkillers regularly.

Once the skin graft and the donor site are well healed, you can go home. This is usually 7–10 days after the operation. You might have to come back to the hospital for dressings. Don't be put off at how the graft area is looking at first. The raw look will heal and fade in time.

Removing lymph nodes

If melanoma cells are found in your lymph nodes, your doctor may decide to remove some of the nodes. This helps to prevent cancer spreading to other parts of your 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. Contact your doctor if you notice swelling or a feeling of heaviness, tightness, soreness or stiffness in the affected area. For more information or free factsheets on preventing and treating lymphoedema, call the National Cancer Helpline 1800 200 700, drop into a Daffodil Centre or visit the website: www.cancer.ie

Going home

If you live alone or have problems getting around the house, talk to the medical social worker or nurse on your ward once you are admitted to the ward. That way, they can organise the community services you may need after you leave hospital. On the day you go home, you will be given a date to come back for a check-up, usually in about 6 weeks' time.

If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, cancer nurse specialist or hospital ward for advice.



To sum up

- Excision surgery is the main treatment for melanoma.
- The aim of surgery is to remove the melanoma and the area close to it.
- Surgery is often the only form of treatment needed.
- You may need a skin graft if a large area of skin is removed.
- If your lymph nodes are affected, you will have surgery to remove them.

National Cancer Helpline Freefone 1800 200 700

Biological (targeted) therapies

Biological (targeted) therapies work with your body. They can help fight cancer, stop it spreading or control side-effects from other cancer treatments. They do this by stopping or slowing the growth of cancer cells or by making it easier for your immune system to destroy them.

There are different types of biological therapies that may be used to treat advanced melanoma. For example, cancer growth inhibitors, monoclonal antibodies and immunotherapy. Some treatments fit into more than one of these groups. Biological therapies don't cure the melanoma but they can control it for a time.

BRAF inhibitors

One type of biological therapy used in the treatment of late-stage melanoma is BRAF inhibitors. BRAF is a gene found inside body cells which can control cell growth. The BRAF gene is mutated in about half of patients with melanoma. This means that cell growth does not switch off when it should and the abnormal cells grow and spread. Your melanoma tissue will be tested for the BRAF gene mutation. If the test is positive you may be treated with a BRAF inhibitor. BRAF inhibitors target the mutation in the BRAF gene and cause the cancer to stop growing.

Vemurafenib: Vemurafenib is a drug commonly used to treat melanoma with the BRAF mutation. Vemurafenib is given as a tablet that you take every day.

What are the side-effects?

The side-effects of vemurafenib include rashes, joint pain, hair loss, tiredness, liver problems and skin complaints. Before you start treatment, do ask your doctor about any side-effects that you can expect. He or she will tell you what to do to make treatment easier.

MEK inhibitors

MEK inhibitors are new drugs used to treat melanoma with the BRAF mutation. They block MEK proteins on the tumour, to stop them helping the cancer cells to grow. You may be given a MEK inhibitor together with a BRAF inhibitor.

What are the side effects?

Side effects of MEK inhibitors include fever and chills, rash, feeling sick (nausea), getting sick (vomiting) and diarrhoea.

Monoclonal antibodies

Monoclonal antibodies can block the growth of cancer cells by interfering with molecules needed for the cancer to grow.

Ipilimumab: Ipilimumab (Yervoy®) is one example of a monoclonal antibody. Ipilimumab is usually injected into your vein in an infusion (drip) lasting 90 minutes. Normally, you receive four doses over three months. Research has shown that ipilimumab may to prolong life in advanced melanoma.

What are the side-effects?

Side-effects of ipilimumab include tiredness (fatigue), nausea, diarrhoea, abdominal pain, numbness or weakness in your face, arms or legs, itching and rashes.

Anti PD-1 drugs: PD-1 is a protein found on the surface of special white blood cells called T-cells. T-cells help your body's immune system fight disease. PD-1 stops the T-cells from working properly. The drugs called PD-1/PDL-1 pathway inhibitor drugs stop PD-1 from working. This means your body's immune system is able to better fight against the cancer.

What are the side-effects?

Some of the side effects of anti-PD-1 drugs are extreme tiredness (fatigue) rashes and diarrhoea.

Immunotherapy

Immunotherapy is a type of biological therapy that boosts your body's immune system to fight cancer.

Interferon: Interferon may be given to try to control advanced melanoma or improve your symptoms. Interferon is given as an injection just under the skin. It can also be given directly into a vein or as a drip (infusion) in hospital.

The dose and length of treatment can vary. But you will be told how often to take the drug and how long treatment will last.

What are the side-effects?

Interferon can cause flu-like symptoms. These include chills, fever, joint pain and headaches. You may also feel very tired or even depressed.

Usually the side-effects disappear once the treatment is over. If you become depressed, you may also need medication. Do ask your doctor for advice. Call the National Cancer Helpline on 1800 200 700 for a free copy of *Coping with Fatigue*. You can also pick up a copy at a Daffodil Centre or download one from our website

www.cancer.ie

**To sum up**

- Biological (targeted) therapies are a type of treatment used to treat advanced melanoma.
- BRAF and MEK inhibitors can be used if you have a mutated BRAF gene.
- Monoclonal antibodies can be used to treat advanced melanoma. For example, ipilimumab (Yervoy®). Ipilimumab can cause fatigue, nausea, abdominal pain, itching and rashes.
- Immunotherapy boosts your body's immune system to fight melanoma.

Chemotherapy

Chemotherapy is a treatment using drugs to control cancer. It is rarely used to treat melanoma. Chemotherapy may be given to control advanced melanoma or improve symptoms. Dacarbazine is the drug normally used to treat melanoma.

You may be given chemotherapy as part of a clinical trial. Clinical trials are research studies investigating the best ways to treat a disease. Your doctor may ask you if you would like to take part in a trial. See page 39 for more details.

What are the side-effects?

The side-effects of chemotherapy vary from person to person. Side-effects of dacarbazine in the short term can include:

- Nausea and vomiting
- Anaemia
- Infection
- Bruising or bleeding

Other side-effects

If you have a side-effect or symptom other than those listed above and it concerns you, tell your doctor or nurse straight away. He or she will tell you what to do. For more information on chemotherapy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the free booklet, *Understanding Chemotherapy*. You can also get a copy of the booklet from our website www.cancer.ie



To sum up

- Chemotherapy is a treatment that uses drugs to control cancer.
- Dacarbazine is a drug normally used to treat melanoma.
- Some side-effects include nausea and vomiting, fatigue, infection, anaemia and bruising.

Radiotherapy

Radiotherapy uses high-energy rays to destroy or shrink cancer cells. It kills the cells while doing as little harm as possible to normal cells. Radiotherapy is generally not used to treat melanoma of the skin. Usually it is used if the melanoma has spread to other parts of your body, such as your brain or spinal cord. Radiotherapy can also help to relieve pain.

Radiotherapy can be given as external beam radiation. This is where a beam of radiation is aimed at the cancer directly from a machine. The machine is called a linear accelerator. The radiation only affects the cells in the treated area and not the rest of your body. Your doctor will let you know how many sessions or treatments you need.

Planning your treatment

First, your doctors and other specialists plan how best to give you the treatment. They work out how to give you the right amount of radiotherapy with the least damage to normal cells.

Treatment planning is a very important part of radiotherapy. It may take a few visits to the radiotherapy department before your treatment can go ahead. On your first visit, you may be asked to lie under a machine called a simulator. This takes X-rays of the area to be treated. Or you might have a CT scan for planning your treatment instead.

The area to be treated will be marked on your skin. These marks are like dots and are made with a permanent tattoo. That way the X-rays can be aimed at the same area each day. Before starting radiotherapy, you will be told how to look after your skin during and after treatment. If you have any queries, do ask your radiation therapist or nurse for advice.

Getting your treatment

External radiotherapy treatment is quite straightforward. You will be asked to come for treatment every day during the week with a rest at weekends. Your treatment can continue for 2–4 weeks. Each treatment session only lasts a few minutes. The treatment is painless but you will be asked to lie still.



Linear accelerator

How much treatment you need will depend on the type and size of the melanoma. Your doctors will discuss this with you.

Each time you come for treatment you will go into a special room. The radiation therapist will ask you to lie or sit in a certain position under the machine. When you are ready the radiation therapist will leave the room. The machine will then be turned on and your

treatment given. Even though you are on your own in the room, your radiation therapist can see you all the time through a closed circuit camera. You can talk through an intercom to the staff if you wish.

What are the side-effects?

The side-effects of radiotherapy depend on the part of your body being treated. You may feel sick or get sick, have redness of the skin, or lose body hair on the treated area. You may also feel tired for some time.

External radiotherapy is safe and does not make you radioactive. If you would like more information on radiotherapy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the free booklet *Understanding Radiotherapy*. A DVD called *Radiation Therapy: A Patient Pathway* is also available.



To sum up

- Radiotherapy is a treatment using high-energy X-rays.
- The X-rays are aimed at the cancer to cure or shrink it.
- Radiotherapy is painless and only takes a few minutes.
- Treatment may continue for 2–4 weeks, depending on the extent of the melanoma.
- Side-effects of radiotherapy depend on the area being treated and the type of radiotherapy given.

Palliative care

If your cancer is advanced it may be very difficult to cure. If this happens, your doctor will discuss the best treatment options for you with the healthcare team. He or she may refer you to specialist palliative care doctors and nurses.

Palliative care is treatment and care given if you are ill due to advanced cancer. The aim of the care is not to cure the disease but to relieve your symptoms and make sure you have the best quality of life possible.

How can I cope with fatigue?

Fatigue is a common symptom of cancer. Fatigue is usually described as an overwhelming tiredness. Often it is not relieved by rest. You may also find it hard to concentrate or even to make decisions. Fatigue may be caused by anxiety over a cancer diagnosis or the added stress caused by treatment. Whatever the reason, there are things you can do that may help.

If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Also, try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

Regular exercise can help too. For example, a 30-minute walk 3 days a week might be a realistic goal and will boost your morale when you achieve it. Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping. Use the extra free time to do something that you especially enjoy.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy. You can also get a copy of the booklet from a Daffodil Centre or download it from our website www.cancer.ie



Hints & Tips – fatigue



- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Eat little and often and use ready-made meals or snacks.
- If you find it hard to sleep, make sure your bedroom is quiet and not too hot or cold.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.

- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Use relaxation techniques to get to sleep. For example, gentle exercise and relaxation tapes.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, cola or chocolate.

Will treatment affect my sex life and fertility?

Intimacy and loss of libido

There is no medical reason why you cannot have sex while you are being treated for melanoma, if you feel like it. But coming to terms with the fact that you have cancer can take a while for some people.

Your emotions might be turned upside down and you might find it hard to relax. You may also feel tired from the effects of treatment. As a result, you may have a loss of desire for sex (libido) and not wish to be intimate with your partner. But remember this is a normal way to feel at this time.

You may be afraid that melanoma can be passed on to a partner during sex. There is no truth to this. It is quite safe for you to have sex again with your partner.

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 too. If you have a supportive partner, you may find that talking about your feelings will help ease your anxiety. Talking to your doctor or nurse might also help. He or she can also refer you a specialist counsellor for help.

Contraception

It's not advisable to become pregnant or father a child while having drug therapies, because the drugs may harm the developing baby. For this reason, your doctor will advise you to use a reliable method of contraception (usually barrier methods such as condoms or the cap) throughout your treatment and for a few months afterwards. You can discuss this with your doctor or nurse.

Many specialists recommend that you wait for 2 years after treatment 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.

Fertility

Your fertility may be affected by some of the melanoma treatments. Sadly, you may not be able to have a child in the future. If this is the case, do talk to your partner about your feelings. Also, discuss your worries about infertility with your doctor. He or she can tell you if there are any options open to you at this time. It may be possible to freeze your eggs or sperm before treatment begins. Rotunda IVF at the Rotunda Hospital, Dublin provides a service where eggs or sperm can be frozen for later use. Talk to your doctor about this service or call the National Cancer Helpline on 1800 200 700 for more information or visit a Daffodil Centre.

Dealing with infertility may not be easy, depending on your age and if you have had children or not. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener.

What follow-up do I need?

After your treatment has ended you will need to come back for regular check-ups. This is called follow-up. Follow-up visits will usually be every 3–6 months, for at least 5 years. Gradually the visits will become less frequent. The follow-up may involve having a skin exam, blood tests, X-rays and scans.

A very important part of your follow-up is making sure that you inspect your skin regularly for any changes in your skin. For example changes in moles or lumps. If you find any changes go to your GP so that he or she can check them. Remember a melanoma that is treated early has a greater chance of being cured.



Self-exam for melanoma

- Examine yourself from head to toe every month.
- Learn the moles, freckles and other skin marks that are normal for you.
- Stand in front of a long mirror.
- Check your front, groin and your back.
- Check your sides with your right and left arms raised.
- Bend your elbows and look carefully at your forearms and upper underarms.
- Look at your fingernails and palms.
- Look at the backs of your legs and feet, even the spaces between your toes and soles.
- Examine the back of your neck and scalp with a hand mirror. Part your hair for a closer look.
- Check your back and buttocks with a mirror.
- Ask a relative or friend to check your back or other hard-to-see areas.
- Take a photograph of your skin every year, especially your back, and compare them.
- Visit your doctor if you notice something that concerns you.



Remember when checking a mole, look for the ABCDE:

- | | |
|--|---|
| A = asymmetrical (uneven) shape | D = diameter (size) |
| B = irregular border | E = evolving (growing or changing over time) |
| C = changes in colour | |

Reducing your risk of further skin cancer

Anyone who has been diagnosed with melanoma may have a higher risk of developing another melanoma. It is very important that protect your skin from UV rays. There are ways to protect your skin. Learn how to protect your skin using the SunSmart code on page 38. If you are unsure, do ask your doctor or nurse for advice when you go for check-ups. You can also visit Daffodil Centre or call the National Cancer Helpline on 1800 200 700.



Children and melanoma

It is rare to see melanoma and other types of skin cancer in children. But if your child is born with a giant birthmark (naevus), there is a slight risk it may change and become a melanoma. From research we know that severe sunburn as a child or adolescent may lead to melanoma later in life. For this reason, do protect your children's skin from an early age. It will reduce the risk of skin damage and melanoma.



All babies under 6 months of age should be kept out of direct sunlight. From the age of 6 months, children should wear protective clothing like a loose T-shirt and hat. Apply a sunscreen with an SPF of 30 or higher and UVA protection when they are out in the sun. This should be reapplied frequently, especially if the child is swimming or playing with water. 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 may be at risk of developing melanoma as well. This includes your brother or sister or children. The level of risk depends on their skin type and the number of unusual-looking moles. Your family member should visit a dermatologist if they are concerned about their skin.

Reduce your risk of melanoma
by following the SunSmart code.

 Irish Cancer Society



Seek shade...

Especially from 11am to 3pm.



Cover up...

By wearing a shirt with a collar and long shorts.



Also wear a hat that gives shade to your eyes, ears and back of your neck.



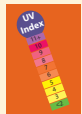
Wear wraparound sunglasses...

Make sure that they give UV protection.



Slap on sunscreen...

Use sunscreen with SPF 15 or higher for adults (SPF 30 or higher for children) and UVA protection.



Check the UV index...

If it is 3 or higher protect your skin when outdoors, even on cool and cloudy days. Find the UV index at www.cancer.ie/UVindex



But don't think that using sunscreen allows you to spend longer in the sun. You will still need to be careful and follow the SunSmart code.

Look for the UVA logo on your sunscreen bottle.

UVA

Visit the SunSmart website at www.cancer.ie/sunsmart



Research – what is a clinical trial?



Research into melanoma treatment goes on all the time.

For example:

- How much skin needs to be removed around a melanoma?
- Are skin grafts needed for melanomas of a certain size and thickness?
- Can new anti-cancer treatments work for melanoma that has spread to other parts of the body?
- Are there new ways to stop or slow the spread of melanoma?
- Do the new drugs work well in the treatment of melanoma?
- When is the best time to give chemotherapy?
- Can high-dose treatments work for patients who in the past were seen as unsuitable for this treatment?
- Can advanced melanoma treatments be used to reduce the risk of a high-risk melanoma returning?
- Can using combinations of drugs work better than using them alone?

Research is also looking at new treatments that destroy cancer cells without harming healthy tissues. These treatments include the use of vaccines and drugs that may help the immune system to fight the cancer. Research on vaccines to prevent melanoma coming back is also taking place.

Taking part in clinical trials

Many patients with melanoma take part in research studies. These are called clinical trials. Your doctor may ask you to try a new treatment. He or she may refer you to another hospital if they feel a clinical trial there may help you. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use. There is no need for worry as you will be carefully monitored during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your melanoma or blood.

For more information, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or visit our website: www.cancer.ie

Cancer and complementary therapies

Complementary therapies are treatments that can be given along with standard medical treatment (conventional therapies). For example, yoga or massage. Some people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country in which you live. In Ireland cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted.

You may hear about the following types of treatments or therapies:

Conventional therapies

Conventional therapies are treatments that doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, hormone therapy and biological therapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- Hypnotherapy

Many people find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism.

Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health. Always talk to your doctor if you are considering an alternative to conventional treatment.



If you decide to have complementary or alternative treatments...



Before you decide to change your treatment or add any methods of your own, do talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, do talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present, this area is not fully regulated in Ireland. Make sure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download the booklet at www.cancer.ie



Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have skin cancer. Different people will have different reactions. Even if you have early stage melanoma, which is often completely curable, you may still feel shocked, worried or upset. There is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until you finish all your treatment that your emotions hit hard.

Common reactions include:

- Shock and disbelief
- Sorrow and sadness
- Resentment
- Fear and uncertainty
- Denial
- Blame and guilt
- Loss of control
- Anger
- Withdrawal and isolation

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet which discusses them in detail is called *Understanding the Emotional Effects of Cancer*. For a copy call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download the booklet at www.cancer.ie

Shock and disbelief

*It can't be me.
Has there been a mistake?
Cancer happens to other
people, not me.*

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are genuinely shocked when it does. Even if your

doctor and nurse discuss the cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you cannot really believe what is happening to you.

Fear and uncertainty

*I'm going to die.
Will it be painful?
Will I become a
different person?*

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. They think the worst. But today many cancers can be cured or controlled with modern treatments. Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers.

You may also have fears that your experience of cancer will change who you are or that people will reject or avoid you. For example, after some cancer treatments your body image may be different, and it will take some time for you and for others to adjust to your new look. You may also have practical worries and fears about the effect of your illness on your family, your finances, your job, and your lifestyle.

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your cancer will come back. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Discuss your concerns with your doctor, nurse or medical social worker, who will give you advice and help. If living with uncertainty overwhelms you, it may help to talk to someone in a support group, such as a Survivors Supporting Survivors volunteer. See page 60 for more information.

Loss of control

*I can't cope with this.
'I'll never get through it.*

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident to make any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

>>> Learning more about your illness and treatment can help you feel more in control.

Sorrow and sadness

*I used to be so healthy.
I had so many plans.
I've let my family down.*

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons. For example, for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment. Depending on your type of cancer, your fertility or body image may be affected by treatment. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but they will gradually fade.

Denial

*I'm fine, really.
I don't have cancer.*

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you do not want to hear any information about your cancer until you are ready.

Anger

*Why me?
I always took care of my health.
Why did this happen now?*

It is normal too to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or if you have a religious belief, you may feel angry with God for allowing cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

Your family and friends may not always be aware that your anger is really at your illness and not at them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. So if it persists and you are finding it hard to talk to your family, tell your nurse or doctor.

Resentment

*How can you talk – you don't have to deal with cancer.
How come I'm not getting better?*

It is natural that you might be resentful and unhappy because you have cancer while other people are well. During the course of your illness feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker than you have.

You may resent having to change your lifestyle in some way.

Sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

>>> Don't bottle up your feelings – express them.

Blame and guilt

*I should've been more careful.
If only I had a more positive attitude, I wouldn't have got sick.*

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time.

Don't feel guilty if you can't keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is no evidence at all that your attitude will affect your health or cancer. Regret and guilt serve no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

Withdrawal and isolation

I just need to be on my own.

It is true that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal for you to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. But it is not a good idea to spend long hours on your own every day.

Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready.

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. If you would like a copy call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download the booklet at www.cancer.ie

Learning to cope

After any treatment for cancer it can take some time to come to terms with your emotions. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, many people are able 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 you more support.



Positive emotions

A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what is important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.



How can my family and friends help?

Family and friends can support you in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Some may gather up-to-date information on melanoma to know what you can expect and what you are going through. Others may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friends best.



How to talk to someone with cancer



When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about.

You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, many do not. Be honest with your own feelings too.

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may think you are not doing much by just listening. In fact, it is one of the best ways to help.

Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

Lost for Words: How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer. If you would like a copy call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download the booklet at www.cancer.ie

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives.

Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or that you're letting them down. These are all natural feelings to have at this time.

Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Children are very sensitive to stress and tension. If you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible, then someone else close to your children should break the news.

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more.

It is best to prepare children for the side-effects of treatment before they happen and to answer their questions simply and honestly. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

Coping with children's emotions

During your illness, your children may experience a range of emotions from fear, guilt and anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, children may feel that they somehow are to blame. But by having an open honest approach, it may bring a sense of relief. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer. If you would like a free copy call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download the booklet at www.cancer.ie

What else can I do?

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- **Live one day at a time:** Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment.
- **Live well:** 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. Do some regular exercise that you enjoy.
- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while for you to adjust to your new routine.
- **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs.
- **Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Ask what side-effects you can expect so you can prepare for them. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health.


- **Find what works for you:** Some people are comfortable taking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you.
- **Build a support network:** Be realistic about what you can manage by yourself. Ask for help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.
- **Seek professional help:** If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If your feelings are still getting the better of you, discuss them with your nurse and doctor. They may recommend you talk to a trained counsellor or other specialist.
- **Spiritual care:** When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to take comfort and support from these practices. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.
- **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. If you would like a free copy call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download the booklet at www.cancer.ie

Support resources

Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.

- | | | |
|----------------------------|-----------------------------|---|
| ▪ Cancer nurse specialists | ▪ Community health services |  |
| ▪ Medical social worker | ▪ Support groups | |
| ▪ Psycho-oncology services | ▪ Irish Cancer Society | |
| ▪ Family doctor (GP) | | |

Cancer nurse specialists: Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse coordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. The nurses work along with other members of your medical team to meet your needs.

Medical social worker: The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on practical and financial support and services available when you go home.

Psycho-oncology services: In some larger hospitals there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

GP (family doctor): You may feel comfortable talking to your family doctor (GP) about your cancer too. He or she can discuss any of your queries and offer advice and support.

Community health services: There are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and

home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as financial problems or exceptional needs. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

Support groups: Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. Cancer support groups and centres are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet. You can search for a support group on www.cancer.ie.

Irish Cancer Society: The staff of the Cancer Information Service will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about financial matters. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for information about any of the services outlined above or for support services in your area.

»»» Remember that there are many people ready to help you

Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of the following are given here:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances

At the end of this section there are also 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 a public hospital. There is a €75 a night charge up to a limit of €750 in 1 year. 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 accident and emergency department of a public hospital without being referred there by a GP, you will be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the accident and emergency department first.

The €100 charge applies to the first visit in relation to an illness or accident. If you have to return for further visits to an outpatient clinic in relation to the same illness or accident, you should not have to pay the charge again.

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 as well as outpatient services and medical appliances. You will have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €500 or less (€900 for couples), you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

If you wish to apply for a medical card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible. To apply for a GP visit card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office or your local pharmacy.

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, Laya Healthcare, AVIVA Health, GloHealth, and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

If you have private insurance, you may not always be able to have your tests done as quickly as you would like. Your health insurer has to approve some tests in advance. For example, MRI and PET scans. In some cases, it may take 24–48 hours to get approval from your health insurer.

Benefits and allowances

You or a family member may qualify for a number of benefits and allowances. For example: Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

More information on these is available in a booklet called *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. For a free copy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie



Application forms for the benefits are available from social welfare offices or the Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 1890 927 770. You can also download the forms from websites such as www.welfare.ie or www.citizensinformation.ie

Appliances

If you have a medical card most appliances such as wigs and prostheses are free of charge or subsidised. The subsidy will depend on the HSE area. For further information, contact your local HSE office.

Travel to hospital

You may be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres, usually for patients with medical cards.

See pages 61 and 62 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS 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:

Dept of Social Protection – Information Service

Oisín House Tel: 1850 662 244
212–213 Pearse Street Leaflet line: 1890 202 325
Dublin 2 Email: info@welfare.ie
Website: www.welfare.ie

For queries about local health and social services, contact the HSE.

HSE infoline: 1850 24 1850 **Email:** info@hse.ie **Website:** www.hse.ie

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

Citizens Information Tel: 0761 07 4000

Email: information@citizensinformation.ie

Website: www.citizensinformation.ie



If you have financial worries...



A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or unemployed, this may cause even more stress. It may be hard for you to recover from cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 61 for more details. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre and the nurses will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 63 for more contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 69 for more information.

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.

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support services
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project

Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline 1800 200 700** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues.

These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The Helpline can also put you in contact with the various support groups that are available. The Helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website **www.cancer.ie** provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- **Message Board** is a discussion space on our website (**www.cancer.ie**) to share your stories, ideas and advice with others.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter** (@IrishCancerSoc).

Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. These have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support services

The Irish Cancer Society funds a range of services set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See pages 63-67 for more details.

Survivors Supporting Survivors

Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides peer support to people who have been diagnosed with cancer. All of the volunteers have had a cancer diagnosis and have been carefully selected and trained to give you support, practical information and reassurance when you need it most. You can speak to someone who really knows what you are going through. If you would like to make contact with a volunteer, please call the National Cancer Helpline on 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the Helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Cancer information booklets and factsheets

Our booklets provide information on all aspects of cancer and its treatment, while our factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. The booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from www.cancer.ie or picked up at a Daffodil Centre.



Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances the Irish Cancer Society may be able to provide limited financial help to patients in need through schemes such as Travel2Care and Financial Aid.

Travel2Care: Travel2Care can help with your travel costs if you have genuine financial hardship due to travelling over 50 kilometres to a rapid access diagnostic clinic for tests or to a designated cancer centre or approved satellite centre for cancer treatment. The scheme is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. Travel2Care can help with some of the costs of public transport, such as trains or buses, private transport costs, or petrol expenses.

If this applies to you, contact the medical social work department in your hospital or speak to your cancer care nurse. You can also contact the Irish Cancer Society on (01) 231 6643 / 231 6619 or email: travel2care@irishcancer.ie

Financial Aid: A special fund has been created to help families experiencing financial difficulty as a result of cancer. If this applies to you, contact the medical social work department in your hospital. You can also speak to your cancer care nurse or contact the Irish Cancer Society at (01) 231 6619.

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 to find out if Care to Drive is available in your hospital.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.



Useful organisations

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

The Carers Association
Market Square
Tullamore
Co Offaly
Freefone: 1800 240 724
Email: info@carersireland.com

Citizens Information
Tel: 0761 07 4000
Email: information@citizensinformation.ie
Website: www.citizensinformation.ie

Get Ireland Active: Promoting Physical Activity in Ireland
Website: www.getirelandactive.ie

Health Promotion HSE
Website: www.healthpromotion.ie

All Ireland Co-operative Oncology Research Group
Website: www.icorg.ie

Irish Nutrition & Dietetic Institute
Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: www.indi.ie

Irish Oncology and Haematology Social Workers Group
Website: http://socialworkandcancer.com

Money Advice and Budgeting Service (MABS)
Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Rotunda IVF
Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email info@rotundaivf.ie
Website: www.rotundaivf.ie

Health insurers

AVIVA Health
PO Box 764, Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth
PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: www.glohealth.ie

Laya Healthcare
Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
LoCall: 1890 700 890
Email: info@layahealthcare.ie
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)
IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support services

Survivors Supporting Survivors
Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline: 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

ARC Cancer Support Centres Dublin
[See page 65]

Brain Tumour Support Group
Medical Social Work Department
St Luke's Hospital
Highfield Road
Rathgar
Dublin 6
Tel: 01 406 5295

Canteen Ireland [Teenage cancer support]
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: info@canteen.ie
Website: www.canteen.ie

Cancer Support Sanctuary LARCC
[See page 65]

Connaught support services

Athenry Cancer Care
Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 845 228 / 091 844 319
Email: athenrycancercare@gmail.com
Website: www.athenrycancercare.com

Cara Iorrais Cancer Support Centre
2 Church Street
Belmullet
Co Mayo
Tel: 097 20590 / 087 391 8573
Email: caraiorrais@gmail.com

East Galway & Midlands Cancer Support
Cluain Mhuire
Brackernagh
Ballinasloe
Co Galway
Tel: 090 964 2088 / 087 984 0304
Email: info@egmcancersupport.com
Website: www.eastgalwaycancersupport.com

Gort Cancer Support Group
Garrabeg
Gort
Co Galway
Tel: 091 648 606 / 086 172 4500
Email: info@gortcancersupport.ie
Website: www.gortcancersupport.ie

Hand in Hand
[Children's Cancer Support Centre]
Main Street
Oranmore
Co Galway
Tel: 091 799 7590
Email: info@handinhand.ie
Website: www.handinhand.ie

Mayo Cancer Support Association
Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: www.mayocancer.ie

Roscommon Cancer Support Group
Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: info@vitahouse.org

Sligo Cancer Support Centre
44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website: www.sligocancersupportcentre.ie

Tuam Cancer Care Centre
Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

Leinster support services

Aoibheann's Pink Tie
[Supporting children with cancer]
Unit 22
Docklands Innovation Centre
128- 130 East Wall Road
Dublin 3
Tel: 01 240 1300
Email: lindaconnell@aoibheannspinktie.ie
Website: www.aoibheannspinktie.ie

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

ARC Cancer Support Centre
ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Arklow Cancer Support Group
25 Kings Hill
Arklow
Co Wicklow
Tel: 0402 23590 / 085 110 0066
Email: info@arklowcancersupport.com
Website: www.arklowcancersupport.com

Balbriggan Cancer Support Group
Unit 23, Balbriggan Business Park
Harry Reynold's Road
Balbriggan
Co Dublin
Tel: 087 353 2872 / 086 164 2234

Cancer Support Sanctuary LARCC
Coole Road
Multyfarnham
Mullingar
Co Westmeath
Tel: 044 937 1971
CallSave: 1850 719 719
Email: info@cancersupport.ie
Website: www.cancersupport.ie

Cara Cancer Support Centre
7 Williamson's Place
Dundalk
Co Louth
Tel: 042 937 4905
Mobile: 087 395 5335
Email: info@ccscdundalk.ie
Website: ccscdundalk.ie

Cois Nore Cancer Support Centre
8 Walkin Street
Kilkenny
Tel: 056 775 2222
Email: coisnorekilkenny@gmail.com
Website: www.kilkennycancersupport.ie

Cuisle Cancer Support Centre
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support Group
Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.dochasoffaly.ie

Dublin West Cancer Support Group
Generic Social Work Department
Oak Unit
Cherry Orchard Hospital
Ballyfermot
Dublin 10
Tel: 01 620 6273
Email: martina.mcGovern2@hse.ie/
noreen.obrien4@hse.ie

Éist Carlow Cancer Support Centre
The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Cancer Support Centre
George's Street
Drogheda
Co Louth
Tel: 041 980 5100
Email: info@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support
La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: info@greystonescancersupport.com
Website: www.greystonescancersupport.com

Hope Cancer Support Centre

22 Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: info@hopesupportcentre.ie
Website: www.hopesupportcentre.ie

Midlands Myeloma Support Group

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie

Rathdrum Cancer Support Group

St Anne's
Lower Street
Rathdrum
Co Wicklow
Tel: 087 925 3915
Email: rathcan@gmail.com

Tallaght Cancer Support Group

Trustus House
1-2 Main Street
Tallaght
Dublin 24
Tel: 086 400 2736
Email: ctallaght@yahoo.ie
Website: tallaghtcancersupport.com

Wicklow Cancer Support Centre

Rear of Butler's Medical Hall
Abbey Street
Wicklow
Tel: 0404 32696
Email: wicklowcancersupport@gmail.com

Munster support services**Cancer Information & Support Centre**

University Hospital Limerick
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: caresupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: info@corkcancersupport.ie
Website: www.corkcancersupport.ie

Cuan House Cancer Support Centre

24 Gort Aoibhinn
Cork Hill
Youghal
Co Cork
Tel: 024 92353

Kerry Cancer Support Group

Acorn Centre
124 Tralee Townhouse Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupportgroup@eircom.net
Website: www.kerrycancersupport.com

Recovery Haven

5 Haig's Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhavenkerry.com

Solas Centre

South Eastern Cancer Foundation
Williamstown
Waterford
Tel: 051 304 604
Email: info@solascentre.ie
Website: www.solascentre.ie

Suaimhneas Cancer Support Centre

2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email: suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre

Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Ulster support services**Coiste Scaoil Saor Ó Ailse**

C/O Ionad Níomh Padraig
Upper Dore
Bunbeg
Letterkenny
Co Donegal
Tel: 074 953 2949
Email: ionadnp@eircom.net
Website: www.scaoilsaor.ie

Crocus: Monaghan Cancer Support Centre

The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965 / 047 62565
Email: crocus.2011@yahoo.com

Cuan Cancer Social Support and Wellness Group

2nd Floor, Cootehill Credit Union
22-24 Market Street
Cootehill
Co Cavan
Tel: 086 455 6632

Other support services**The Bella Rose Foundation**

Merry Maid House
West Park Campus
Garther's Lane
Citywest
Dublin 24
Tel: 087 320 3201
Email: thebellarosefoundation@gmail.com
Website: www.bellarose.ie

Ballinasloe Cancer Support Centre

Main Street
Ballinasloe
Co Galway
Tel: 090 964 3431
Email: ballinasloecancer@yahoo.co.uk

Cancer Care West

72 Seamus Quirke Road
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Cúnamh: Bons Secours Cancer Support Group

Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Dundalk Cancer Support Group

Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

The Forge Cancer Support Service

The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924
Email: theforgefrc@eircom.net

Killybegs Cancer Support Group

Kille
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Newbridge Cancer Support Group

Tel: 083 360 9898
Email: newbridgecancerhealinghelp@gmail.com

Purple House – Cancer Support

Aubrey Court
Parnell Road
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@purplehouse.ie
Website: www.purplehouse.ie

Sláinte an Chláir: Clare Cancer Support

Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

Solace: Donegal Cancer Support Centre

St Joseph's Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

For other support groups or centres in your area, call 1800 200 700.

Useful contacts outside Republic of Ireland

Action Cancer

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society (US)

Website: www.cancer.org

Cancer Focus Northern Ireland

40-44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Buddies Network

Website: www.cancerbuddiesnetwork.org

Cancer Research UK

Tel: 0044 20 7242 0200
Website: www.cancerhelp.org.uk

Healthtalkonline (UK)

Website: www.healthtalk.org

Macmillan Cancer Support (UK)

Tel: 0044 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
77-81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net
Website: www.cancerni.net

National Cancer Institute (US)

Website: www.nci.nih.gov



Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *A Time to Care: Caring for Someone Seriously Ill at Home*
- *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families.*
- *Journey Journal: Keeping Track of Your Cancer Treatment*



Cancer at Your Fingertips

Val Speechley & Maxine Rosenfeld
Class Publishing, 2001
ISBN 978-1859590362

Challenging Cancer: Fighting Back, Taking Control, Finding Options

Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 978-1859590683

The Chemotherapy and Radiation Therapy Survival Guide: Information, Suggestions, and Support to Help You Get through Treatment

Judith McKay, Nancee Hirano & Myles E Lampenfeld
New Harbinger, 1998
ISBN 978-1572240704

101+ Square Meals

[Budget and nutrition]
Norah Bourke et al
MABS/HSE West/Paul Partnership/Limerick VEC/Safefood, 1998
ISBN 187407514X
[For more details see www.mabs.ie]

Explaining cancer to children

The Secret C: Straight Talking About Cancer

Julie A Stokes
Winston's Wish, 2000
ISBN 978-0955953927

Why Mum? A Small Child with a Big Problem

Catherine Thornton
Veritas, 2005
ISBN 978-1853908910

Helpful DVD

Understanding Radiation Therapy: A Patient Pathway

Call 1800 200 800 for a copy.
Website: www.cancer.ie

What does that word mean?

Abdomen	The part of your body that lies between your chest and hips. Sometimes known as the belly or tummy.
Adjuvant treatment	Treatment for cancer given soon after surgery.
Alopecia	Loss of hair. No hair where you normally have hair.
Benign	Not cancer. A tumour that does not spread.
Biological therapies	A treatment that works with your immune system. It can help fight cancer or control side-effects from other cancer treatments. It does this by stopping or slowing the growth of cancer cells or by making it easier for your immune system to destroy them.
Biopsy	Removing a small amount of tissue from your body to find out if cancer cells are present.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
Chemotherapy	Treatment using drugs that cure or control cancer.
Dermatologist	A doctor who specialises in skin diseases and conditions.
Fatigue	Ongoing tiredness often not helped by rest.
Immunotherapy	Treatment using drugs that boost your immune system to kill cancer cells. See also biological therapies.

Malignant	Cancer. A tumour that spreads.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Melanin	A pigment that gives your skin its colour.
Melanocytes	The cells in your skin that make the pigment melanin.
Melanoma	A skin cancer that affects the melanocytes in your skin.
Metastasis	The spread of cancer from one part of your body to other tissues and organs.
Nausea	Feeling sick or wanting to be sick.
Oncology	The study of cancer.
Palliative care team	A team of doctors and nurses who are trained in managing pain and other symptoms caused by cancer. They will also help you and your family cope with any emotional distress.
Prognosis	The expected outcome of a disease.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radiotherapy	The treatment of cancer using high-energy X-rays.
Sentinel node biopsy	Removing a sample of the lymph node nearest to the melanoma to find out if cancer cells are present.
Staging	Tests that measure the size and spread of cancer

Questions to ask your doctor

Here is a list of questions that you might like to ask. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

- What is melanoma?
- How long will it take to get the test results?
- What stage is my cancer at?
- What type of treatment do I need?
- Will surgery cure my cancer?
- Are there other treatment options? Why is this one best for me?
- Would I be suitable for a clinical trial?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- What side-effects will I get?
- Is there anything I can do to help myself during treatment?
- Will treatment affect my fertility?
- How often will I need check-ups?
- 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 _____

Answer _____

5 _____

Answer _____



Notes



Notes



Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or previous editions:

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Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you would prefer to phone or write to us, see contact details below.

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 at CallSave 1850 60 60 60 or email **fundraising@irishcancer.ie**

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4

Tel: 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

National Cancer Helpline Freephone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

Find us on Facebook

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